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**Life changing diagnoses: how individuals and family
members have experienced and coped with a life impacting
diagnosis.**

**By
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**A thesis submitted in partial requirements for the degree of Doctor
of Clinical Psychology (DClinPsych)**

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List of Abbreviations

APA	American Psychiatric Association
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
DCP	Division of Clinical Psychology
DoH	Department of Health
DSM-IV	Diagnostic and Statistical Manual of mental disorders – fourth edition
DSM-5	Diagnostic and Statistical Manual of mental disorders – fifth edition
ICD-10	International Classification of Diseases – Version 10
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
POMS	Profile of Mood States (measure)
SCIE	Social Care Institute of Excellence
SES	Socio Economic Status
WHO	World Health Organization

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This is for them.

Declaration

This thesis was carried out under the academic supervision of Ms Jo Kucharska, Mrs Jacky Knibbs (Clinical Tutors at the Coventry and Warwick Clinical Psychology Doctorate) and under the clinical supervision of Dr Tim Lacey (Clinical Psychologist).

Apart from the above collaborations, I can confirm this thesis has been composed by myself and no other person and has not been submitted in any previous application for any degree.

This thesis is submitted in support of my application for the degree of Doctor of Clinical Psychology.

The nominated journals for publication of chapters 1, 2 and 3 respectively are: Social Science and Medicine, Research in Autism Spectrum Disorders and Reflective Practice International and Multidisciplinary Perspectives (see Appendices 1-3 for instructions to authors). Authorship of any publications arising from this thesis will be shared with the above supervisors/collaborators where appropriate.

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Summary of thesis

This thesis aims to explore how individuals and family members have experienced and coped with a life changing diagnosis. Diagnoses are an integral part of medical, physical health and psychological settings. A diagnosis can significantly affect individuals and their families. This thesis explores how individuals and their family members can be supported to cope with a life changing diagnosis.

Chapter one is a literature review investigating how religiosity is used by individuals newly diagnosed with breast cancer. After databases and manual searches, fourteen papers that met the inclusion criteria were critically evaluated. Despite the methodological constraints and the conceptual confusion surrounding religiosity, the predominant finding was the double pronged effect of religiosity. Some individuals found religious coping provided them with comfort and meaning making, whereas others found religious coping was associated with negative adjustment to the breast cancer diagnosis. The clinical implications of these findings are discussed in relation to how individuals can be supported using religiosity when diagnosed with breast cancer.

Chapter two is a qualitative exploration of parents' experiences of caring for their child diagnosed with Asperger Syndrome (AS) in adulthood. Eight participants were interviewed using a semi-structured interview and these were analysed using Interpretative Phenomenological Analysis (IPA). Three themes emerged: 'Parenting the unknown', 'Services fumbling in the dark' and 'Fear of the future'. All themes were heavily influenced by the lack of understanding of AS amongst professionals and parents. These themes are considered in relation to service provisions for adults with AS and their parents.

Chapter three is a reflective account of the researcher's experience of the interview process of IPA and the dilemmas of shifting from a clinician to a researcher. The researcher further reflects on diagnostic labels, specifically the removal of AS from the Diagnostic Statistical Manual of Mental Disorders-fifth edition.

Chapter 1

Coping with a diagnosis of breast cancer: The role of religiosity

In preparation for submission to Social Science and Medicine
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1.1 Abstract

A diagnosis of cancer is associated with elevated levels of psychological distress and a potentially imminent mortality. Religious coping is increasingly being recognised as a positive resource to facilitate adjustment to health related stress, especially where this is a health threat or physical suffering. This review critically evaluated studies that explored the use of religious coping strategies when newly diagnosed with breast cancer. Five databases were searched using terms related to cancer, diagnosis, religiosity and coping. Fourteen (quantitative and qualitative) studies met the inclusion criteria. Despite the methodological limitations, especially around how religiosity was measured and its conceptual confusion with spirituality, the findings were tentatively discussed. The predominant finding was the use of a range of positive and negative religious coping strategies in the first six months of a breast cancer diagnosis. Positive religious coping helped individuals positively adjust to their cancer diagnosis, as it provided them with a source of comfort and encouraged meaning making. Negative religious coping strategies led to poor adjustment such as increased levels of low mood. However, some of the findings were contradictory and religious coping was influenced by other factors. The clinical implications are discussed. Future research would benefit from further qualitative research, which would not be restricted to the use of crude measures of religiosity.

Keywords: Newly diagnosed, breast cancer, coping, religiosity

1.2 Introduction

1.2.1 Diagnosis

Diagnoses are often used in psychological and medical settings and can have significant effects on the individual (Division of Clinical Psychology, 2013). This review aims to look at the role of religiosity in those newly diagnosed with a life changing diagnosis of breast cancer.

1.2.2 Cancer

Cancer is a generic term, used to explain a large group of diseases that affect the body. It does not discriminate and affects people all over the world regardless of race, gender, age or culture (World Health Organization [WHO], 2014). Globally it is one of the leading causes of death, accountable for 8.2 million in 2012 (WHO, 2012). In 2012, 14.1 million people were diagnosed with cancer and 32.6 million people were living with cancer (WHO, 2012). It is therefore crucial to investigate how people cope with a life impacting diagnosis.

A cancer diagnosis is associated with a potentially imminent mortality (WHO, 2014) and can negatively impact the individual and their families. Zabora, Brintzenhofesoc, Curbow, Hooker and Piantadosi (2001) found a cancer diagnosis

is associated with elevated levels of psychological distress, irrespective of the cancer site. Individuals diagnosed with cancer are reported to feel a number of different emotions simultaneously such as shock, denial, fear, worry and hopelessness (Lu, Lin & Lee, 2010). Tjemsland, Soreides and Malts (1996) found that receiving a diagnosis of cancer was associated with post traumatic stress disorder symptoms, such as high levels of intrusive thoughts, anxiety and acute symptoms of post traumatic stress. A cancer diagnosis can also negatively impact on significant others in the individuals life (Sprung, Janotha & Steckel, 2011). A diagnosis of cancer can therefore be a highly stressful and traumatic time, making it important to consider how individuals cope.

1.2.3 Coping with cancer

In order to understand how individuals cope with cancer, it is important to look at the operational definition of coping.

Lazarus (1993) defined coping as:

'On-going cognitive and behavioural efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus, 1993, p. 237).

Lazarus (1993) proposed that there are two functional components to coping, which are problem focused and emotion focused. Problem focused coping

involves acting on the environment or the self to elicit change in the stressor. Emotion focused coping involves changing the way the individual attends to the stressor. For example, an individual may avoid or change the way the stressor is perceived and related to, reducing the impact of the stressor whilst the stressor has not changed (Lazarus, 1993).

Cancer is usually perceived as something which is out of the control of the individual (Lu et al., 2010) and therefore potentially eliciting emotion focused coping. Lazarus (1993) reported that if a condition is perceived to be unchangeable, emotion focused coping strategies dominate, as changing the relational meaning can help to regulate the impact of stress and emotions. Religion has been likened to an emotion focused coping strategy, as it can help alleviate existential concerns such as life after death (McFarland, Pudrovskaya, Schieman, Ellison & Bierman, 2013).

Individuals cope with a diagnosis of cancer using a variety of coping strategies. Kissil, Nino, Ingram and Davey (2014) found African American women cope with a breast cancer diagnosis by utilising community support, building a relationship with the cancer, highlighting the positives and using religion and spirituality. Lu et al. (2010) also found Taiwanese women diagnosed with breast cancer used similar coping strategies. Hack and Degner (2004) reported women who coped with their cancer diagnosis using passive cognitive avoidance (acceptance and resignation) had the worst levels of psychological adjustment three years later. This was in

comparison to women who coped using positive re-appraisal and social support, and had better psychological adjustment three years later. This was further shown by Roberts, Czajkowska, Radiotis and Korner (2013) who reported individuals with skin cancer who used avoidant coping strategies (behavioural avoidance) experienced distress in comparison to those who did not use avoidant coping strategies. This suggests not all coping strategies reduce psychological distress.

1.2.4. Religiosity and Spirituality: Conceptual confusion

The conceptual confusion between religiosity and spirituality has made it difficult to study the effects of religion solely, as studies usually view religiosity and spirituality synonymously (Miller & Thoresen, 2003).

Religion and spirituality are viewed to be similar but are conceptually different. Both are multi-dimensional and people who are religious may view themselves as spiritual, but spirituality may or may not be rooted in a religion (Miller & Thoresen, 2003). A particular difference between religion and spirituality are their association with the 'sacred' (Zinnbauer & Pargament, 2005). The sacred in religiosity is referred to as God and in spirituality it is referred to as a higher power or transcendent being. Religiosity is seen as a search for significance in relating to the sacred, whereas spirituality refers to a search where the sacred is the ultimate destination (Zinnbauer & Pargament, 2005). Religion is seen as an institutional phenomenon, which is defined by its boundaries. Religions can be differentiated

by their particular beliefs and practices, may require membership and have an element of social organisation (Miller & Thoresen, 2003). God may be seen as an intimate secure attachment figure, which individuals use for comfort during stressful times (Kirkpatrick, 2004) further differentiating religiosity and spirituality. Religion has been described as having both an extrinsic and intrinsic orientation, which can help operationalise measures. An extrinsic orientation refers to individuals who use religion for a sense of solace, security and distraction. An intrinsic orientation refers to individuals who 'live their religion' and appear to be more adhered to their religious beliefs and rules (Allport & Ross, 1967).

Religion has been described as a latent construct. This means that the underlying entities cannot be observed directly but can be inferred from observations of their component dimensions, such as their cognitions and behaviours, potentially making it feasible to measure (Miller & Thoresen, 2003). Many outcome measures focus on religious rather spiritual variables such as frequency of church attendance (Pargament, Koenig & Perez, 2000; Miller & Thoresen, 2003).

1.2.5. Religion and cancer

The role of religion in physical health has been greatly researched. A review which used a 'levels-of-evidence approach'¹ found religion and spirituality could act as a

¹A review using a levels-of-evidence approach is where studies that meet minimal acceptable methodological standards as set out by the author are included in the review. This approach allows

protective coping resource that reduces the risk of mortality from disease in healthy people. This was mainly due to church/service attendance (Powell, Shahabi & Thoresen, 2003). Barton-Burke, Baretto and Archibald (2008) reported religion is one of the main resources individuals utilise to make sense of suffering, as many religions try to explain or give meaning to distress.

A review by Siegel, Anderman and Schrimshaw (2001) found religious cognitions and activities may facilitate adjustment to health related stress, especially where there are health threats and physical suffering. Thunè-Boyle, Stygall, Keshtgar, Davidson and Newman (2011) examined the impact of a cancer diagnosis on patients' religious beliefs. They found patients belief in God, strength of faith and private religious practices were significantly higher when diagnosed with cancer, in comparison to retrospective reports of a year prior their diagnosis. Research has shown that religion can be positively used to cope with a diagnosis of cancer (Balboni et al., 2007; Elsheshtawy, Abo-Elez, Ashour, Farouk & El Zaafarany, 2014). However, some studies have found negative religious coping, such as abandonment by God were associated with significantly poorer functioning in cancer patients (Sherman, Simonton, Latif, Spohn & Tricot, 2005). The research in this area is therefore contradictory and as noted by Jenkins and Pargament (1995) is surrounded by crude measures of religiosity and conceptual confusion. This review will specifically look at how religion is used by those newly diagnosed with

the researcher to critique studies, in which bias and confounding variables have been minimised. (Powell, Shahabi & Thoresen, 2003).

breast cancer, as studies have investigated how religion is used by cancer survivors (Schreiber & Brockopp, 2012) and during treatment (Obeidat, Lally & Dickerson, 2012).

1.2.6. Rationale

The research on religion and cancer appears to be expanding and a number of reviews have investigated how religious and spiritual coping strategies affect illness adjustment and psychological well being in cancer patients (Schreiber & Brockopp, 2012; Thunè-Boyle, Stygall, Keshtgar & Newman, 2006). However, these reviews used the terms religiosity and spirituality synonymously, making it difficult to determine the extent to which the results can be attributed to religious coping and generally explored the use of religious/spiritual coping throughout the entire cancer process (Thunè-Boyle et al., 2006). To date, no review has considered the role of religion in people newly diagnosed with breast cancer. This review was initially aiming to explore the use of religion in those irrespective of the cancer site. However, having completed steps one and two of the systematic search and study selection (see section 1.3.4) only one study which met the inclusion criteria was conducted with participants who did not have a breast cancer diagnosis. This review therefore focused and aimed to systematically evaluate research regarding the use of religion in those newly diagnosed with breast cancer, to explore the role of religiosity as a coping resource around this significant life changing time. It is hoped this review will contribute to how

services deliver a diagnosis of cancer and how religious coping strategies may be incorporated into support packages.

For this review studies were only included if they stated participants were newly diagnosed and/or seen within 6 months post diagnosis or surgery, as a review of the literature, which stated that the participant sample were newly diagnosed with cancer were mainly seen within this time frame (Cheng, Jackman, McQuestion & Fitch, 2014; Mertz et al., 2012; Turner, Kelly, Swanson, Allison & Wetzig, 2005).

This review aimed to address some of the limitations identified in previous reviews. Firstly, qualitative articles were included, as they can offer an in depth understanding of how religious coping is used by individuals, especially as many measures of religiosity can be crude and measure religion in reductionist or global terms (Stefanek, McDonald & Hess, 2005). Secondly, only studies with clear reports of religious outcomes were included, as even though spirituality and religiosity are similar they are conceptually different (Miller & Thoresen, 2003).

1.3. Method

1.3.1. Search strategy

Search terms were informed by the research aim and the literature in this area. Four conceptual search terms were used, some of which had additional variations (See table 1.1). All the terms were combined using the Boolean operator 'AND' and a truncation on the term 'religion' was used to capture variation in the terminology.

Table 1.1 Search terms

Concept	1. Religion	2. Cancer	3. Diagnosis	4. Cope
Search term	Relig*	Cancer	Diagnosis	Cope
Additional variation	Faith		Surgery	Cope Coping

*Note. Terms taken from Concepts 1, 2, 3 and 4 were combined using the Boolean operator "and". * represents a truncation to capture variation in the terminology.*

1.3.2. Data sources

Initially the Cochrane and DARE database were searched to ensure the review was an original contribution to the literature on the use of religion in health.

Identified search terms were entered into Medline (Ovid), Psychinfo, Scopus, Web of Science and CINAHL from the 30.09.14 to 06.10.14 and again on the 23.03.15. These search engines were chosen because they provided access to journals that represented the psychological and medical nature of the review. All databases were searched by keyword and/or abstract and not restricted to a particular time frame. Studies published after March 2015 were not considered for this review.

1.3.3. Selection criteria

The articles retrieved were assessed for eligibility by applying the inclusion and exclusion criteria (see table 1.2).

Table 1.2: Inclusion and Exclusion Criteria

Inclusion Criteria
1. Participants newly diagnosed with breast cancer. Articles were included if the participant was seen within 6 months of receiving their diagnosis or surgery.
2. Religion had to be an important aspect of the article and therefore be present in the title or abstract. The presence of religion could be present in either the aims or outcome.
3. Articles published in peer reviewed journals
4. Articles written in the English language

Exclusion Criteria

1. Evidence of co-morbid mental illness
 2. Articles where there was major conceptual confusion between religiosity and spirituality.
 3. Articles looking at how religion was used to cope with cancer at points other than at time of diagnosis. For example: articles looking at coping with the end stage of cancer.
 4. Articles written in a non-English language
 5. Articles in the form of a review, commentary, book chapter, letter, conference proceeding, discussion piece or legal paper and if part of a non-published thesis.
-

1.3.4. Systematic search and study selection**1.3.4.1. Step 1**

Initially 618 articles were retrieved through the databases. After removing non-relevant and duplicated articles, this left 210 articles. Of these articles, titles and abstracts were screened against the inclusion and exclusion criteria. This produced 49 articles, which were assessed for suitability. From this 11 met the inclusion criteria.

1.3.4.2. Step 2

The reference lists of the 11 articles were hand searched. This revealed 31 articles of which 3 met the inclusion criteria. Further hand searches of the reference list revealed 7 articles of which none met the inclusion criteria. The study selection process is detailed in figure 1.1, in accordance with PRISMA group guidance (Liberati et al., 2009)

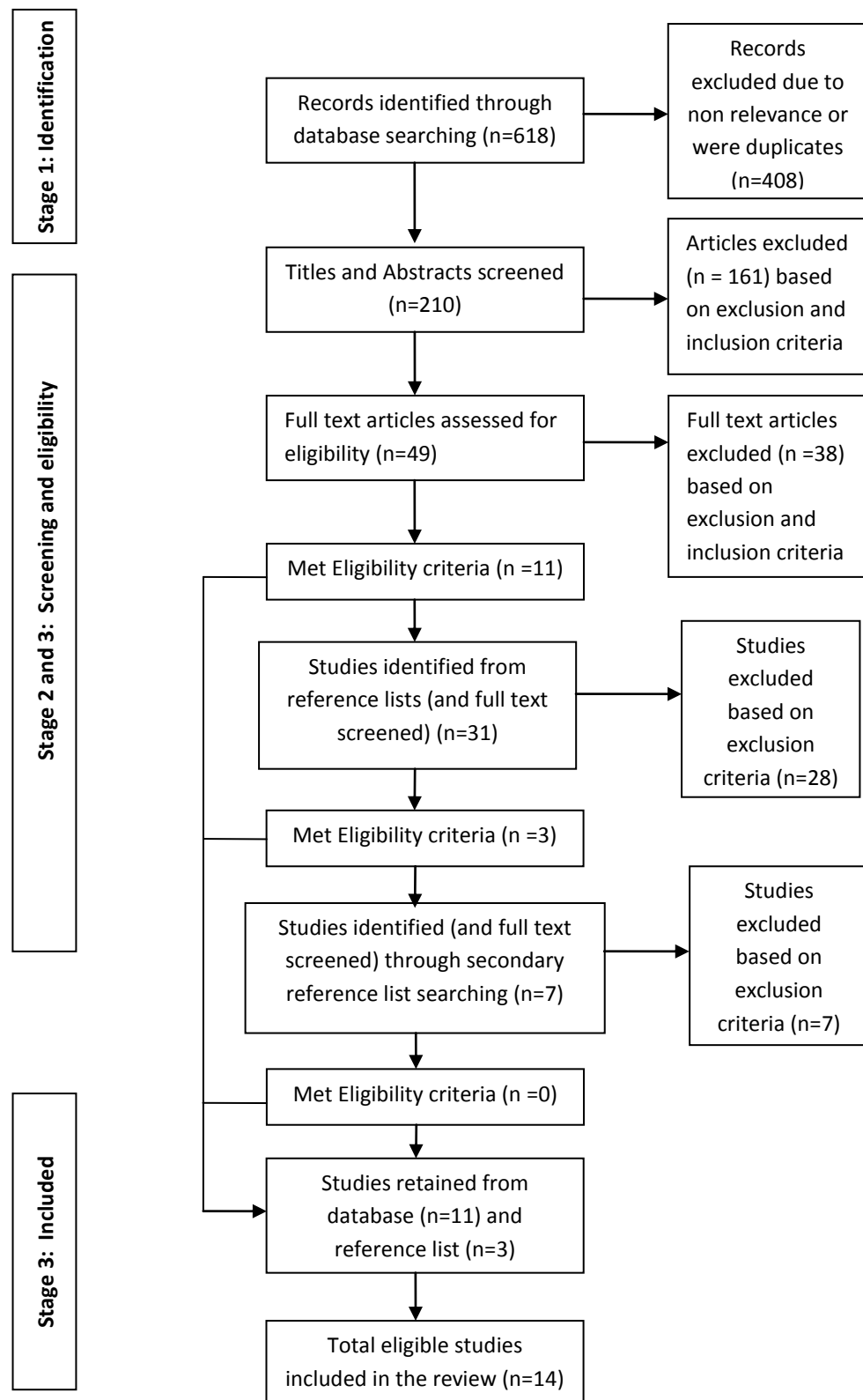


Figure 1.1 PRISMA flow diagram outlining the study selection process (Liberati et al., 2009).

1.3.5. Quality framework

In order to assess the quality of the studies in this review the quality framework developed by Caldwell, Henshaw and Taylor (2011) was used and slightly adapted to enhance the critique of the research (see appendix 4). These adaptations were informed by the framework developed by Kmet, Lee and Cook (2004).

1.3.5.1. Method for assessing quality

The articles were rated against each criterion on the quality framework. Each quality criterion was scored 2 if answered yes, 1 if answered partially and 0 if answered no. The total score was then calculated and converted into a percentage (qualitative articles = maximum score of 36 and quantitative articles = maximum score of 38). To ensure consistent quality ratings, the guidance notes by Caldwell et al. (2011) and Kmet et al. (2004) were used.

In order to establish reliability of the quality ratings, one article which was randomly selected, was independently rated by another reviewer. Whilst this identified discrepancies on a few of the quality criterion, the discrepancies differed by one point and the overall quality score differed by only one point (2%).

1.3.5.2. Summary of the quality assessment

The mean percentage score of the quantitative research was 81% with a range of 68-87%. The mean percentage score of the qualitative research was 76.5% with a range of 64-92% (see appendix 5). Higher scores indicated studies of higher quality. This review did not exclude research on receiving a lower quality score but took this into account when critically appraising the findings. This assessment highlighted methodological weaknesses and potential biases in the studies, some of which are summarised below.

Many of the studies recruited participants from public or private hospitals and represented a sample that was willing to participate in research. This may have resulted in a selection bias. The demographic characteristics of those that did not participate were not always provided (e.g. Culver, Arena, Antoni & Carver, 2002). Some of the participant sample groups were relatively small, which makes it difficult to determine the power of the analysis (e.g. Alferi, Culver, Carver, Arena & Antoni, 1999; Ebright & Lyon, 2002). Only one study had a control group of which to compare the participants with cancer to (e.g. Gall, Guirguis-Younger, Charbonneau & Florack, 2009). Additionally, the participants of all the studies in this review were females, restricting the findings of this review.

Some of the qualitative studies appeared to lack a rationale behind the methodological analysis approach chosen (e.g. Taleghani, Yekta & Nasrabadi,

2005) and provided no information on the epistemological position or reflective stance of the researcher (e.g. Feher & Maly, 1999). Both of which may have affected the interpretation of the interview data.

1.3.6. Data synthesis

The framework developed by Aveyard (2010), which involves interpreting rather than summarising the data was used to synthesise the data (See appendix 6). This approach is similar to a thematic analysis, which involves the identification of salient themes and summarising the literature under thematic headings (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005). A thematic analysis is an effective way to integrate qualitative and quantitative evidence (Dixon-Woods et al., 2005).

Table 1.3: Overview of reviewed studies

Author, Year and Country	Aim(s)	Participant sample (detailed demographic details see appendix 7)	Religiosity Measure	Study design and Statistical analysis	Key Religiosity Findings	Quality score (%)
Alferi, Culver, Carver, Arena & Antoni, 1999 USA	Examine the relationship of religiosity to religious coping and distress in Hispanic women newly diagnosed with breast cancer.	Recruited from a breast health centre (Miami-dade) public hospital. N=49 Assessed 7-10 days, 3, 6, 12 months post surgery. Mean age 56.37 years.	Religious involvement items taken from general social survey (Davis & Smith, 1989).	Longitudinal design Multiple regression analysis t-tests	Evangelical women who used religion to cope showed lower levels of distress and Catholic women who used religion to cope showed higher levels of (non-significant) distress.	81%
Culver, Arena, Antoni & Carver 2002 USA	To investigate the way women of different ethnicities with breast cancer cope across the first year of receiving a breast cancer diagnosis.	Recruited from University of Miami oncology clinic and a breast health centre at Dade county's public hospital. N=131 combined from two samples Assessed 2 days pre-surgery, 7-10 days, 3, 6 and 12 months later. Sample 1 N = 75 Mean Age 53.72 Sample 2 N = 56 Mean Age 56.29	Brief COPE (carver, 1997) Religious item = 'use of religion'	Longitudinal design Repeated measures ANOVA	The African American and Hispanic women used religious coping strategies significantly more than the Non-Hispanic women	87%

Ebright & Lyon 2002 USA	To investigate factors that influence hope at 1-3 & 10-12 months post a breast cancer diagnosis.	Recruited through five Midwestern physicians. N=73 Data collected 1-3 & 10-12 months post surgery. Age (%) Under 50 years 40% Over 50 years 60%	Question: What extent are your religious beliefs helpful as you go through treatment for breast cancer?	Longitudinal design Multiple regression analysis	Helpfulness of religious beliefs significantly influenced women's appraisal of coping.	68%
Feher & Maly 1999 USA	To explore the role of religion in elderly women newly diagnosed with breast cancer	Recruited from eight sites including community, hospital and private breast cancer or oncologic practices. N=33 All seen within 6 months of receiving a diagnosis Mean age 74.4 years	Semi structured interviews	Content analysis	The participant's religious faith provided them with emotional support, social support and meaning to cope with their breast cancer diagnosis.	70%
Gall, Charbonneau & Florack, 2011 Canada	Investigate the role of three aspects of religiosity as potential correlates of perceived growth (positive change or benefit finding) in women newly diagnosed with breast cancer.	Recruited from a breast health clinic. Assessed pre diagnosis, 6, 12 and 24 months post surgery N=87 Mean Age in years 60.95	3 single items to assess religious openness and participation. God image scale (Lawrence, 1997). God image descriptors (Gorsuch, 1968). Sub scaled version of the RCOPE (Pargament, Koenig & Perez, 2000).	Longitudinal design Stepwise Regression analysis Cross-sectional and longitudinal correlations	Findings were contradictory. Some forms of religious coping were associated with positive growth, whilst others showed no relationship or a negative relationship with positive growth.	79%

Gall, Guirguis-Younger, Charbonneau & Florack, 2009 Canada	To assess the negative and positive forms of religious coping from pre diagnosis to 2 years post diagnosis in women with breast cancer.	Recruited from a breast health clinic. Assessed 2-4 days pre diagnosis, 1 week pre-surgery, 1, 6, 12 & 24 months post surgery. N=87 cancer diagnosis group. Mean age = 60.95 years N=151 benign diagnosis group. Mean age = 52.7 years	3 single items to assess religious involvement. Sub scaled version of the RCOPE (Pargament, Koenig & Perez, 2000).	Longitudinal design Repeated measures ANOVA Stepwise regression	The breast cancer group showed significantly more use of the religious coping strategies than the benign diagnosis group.	87%
Herbert, Zdaniuk, Schulz & Scheier 2009 USA	To investigate whether changes in positive and negative religious coping strategies predict changes in wellbeing over time.	Recruited from hospitals in Western Pennsylvania. N=284 Assessed within one month of treatment (T1). Follow up 8-12 months after T1 (T2). Mean age 51 years	Sub scaled version of the RCOPE (Pargament, Koenig & Perez, 2000).	Longitudinal design Pearson correlation Multiple linear regression 2x2 repeated measures ANCOVA	Negative religious coping strategies used at T1 were associated with worse overall mental health, depressive symptoms and less life satisfaction. Effect size = 0.4	81%
Jim, Richardson, Golden-Kreutz & Anderson, 2006 USA	To examine the relationship between how women cope with their breast cancer diagnosis and their self reported meaning in life two years later.	Recruited from a university affiliated cancer institute or self and physician referrals. N=167 Assessed 36 days after surgery and 12 months post diagnosis. Mean age = 51 years	A sub scaled version of the COPE (Carver, Scheiber, & Weintraub, 1989) one item on religious coping.	Longitudinal design Hierarchal multiple regression	Individuals who used religious coping strategies at time of diagnosis made sense of their diagnosis in a spiritual way.	81%

Landmark, Strandmark & Wahl 2001 Norway	To explore women's experiences of being newly diagnosed with breast cancer	Recruited from an outpatient oncology clinic N= 10 Norwegian women Mean time from diagnosis to interview = 8.4 months. 2 participants were seen 12 months post diagnosis. Mean age 50.7 years	Semi structured interviews	Grounded theory (Glaser & Straus, 1967; Straus & Corbin, 1990)	Five themes were identified. One of which was about religious beliefs and doubts.	92%
Northouse 1989 USA	To explore the psychosocial adjustment concerns of newly diagnosed breast cancer patients and their husbands	Recruited from four hospitals in Michigan N=50 Assessed 1-6 days post surgery (Time 1) and 30 days after Time 1 Mean age = 50.4 years	Semi structured interviews	Content analysis	The participants with breast cancer used their religion for strength to cope with their cancer diagnosis.	64%
Pedersen, Christensen, Jensen & Zachariae 2013 Denmark	To investigate the prevalence of religious faith in a secular society of Danish women with breast cancer and to explore if socio-demographic and clinical factors influence this.	Data was taken from a nationwide breast cancer inception cohort of Danish women surgically treated for early stage breast cancer. N=3,343 Completed questionnaires 3-4 months post-surgery Median age = 55.7 years.	Do you believe in God or a higher power? Do you believe your faith has positively influenced your... ➤ ...quality of life in relation to your illness? ➤ ...your cancer illness? Has it made you attend church more?	Longitudinal design Frequency data	Those with a high level of faith perceived their faith to influence the course of their breast cancer and have a positive influence on their quality of life in comparison to those with some faith.	74%

Stanton, Danoff-Burg & Huggins, 2002 USA	To investigate whether women's elected coping strategies and their levels of hope were able to predict adjustment from diagnosis throughout the first year.	Recruited from universities affiliated hospitals and a surgical practice affiliated with a community hospital. N=70 , Baseline measures (1 week pre-surgery). Adjustment measured at 3 months and 1 year post diagnosis Mean age 52.63 years	COPE (Carver et al., 1989) 'I try to find comfort in my religion'	Longitudinal design Repeated measure ANOVA Hierarchal multiple regression analysis	Positive adjustment to the breast cancer diagnosis was associated with women who had low levels of hope and were more likely to use religious coping.	87%
Taleghani, Yekta & Nasrabadi, 2005 Iran	To explore the coping strategies used by Iranian women diagnosed with breast cancer.	Recruited from a hospital. N=19 Muslim women Interviewed 2-10 weeks post surgery mean age 43.7 years	Semi structured interviews	Content Analysis	Five themes were identified. The most salient theme was 'facing the disease using a religious approach	80%
Thunè-Boyle, Stygall, Keshtgar, Davidson & Newman, 2013, UK	To assess the beneficial and harmful effects of religious and spiritual coping on adjustment during the first year of receiving a breast cancer diagnosis.	Recruited from two London UK Teaching hospitals. N=155 85% of participants seen 3 days after surgery, remainder completed questionnaires at a later date. Mean age 55.7 years	Items examining beliefs in the existence of God (Holland et al., 1998). Items examining private and public religious and spiritual factors* RCOPE (Pargament, Koenig & Perez, 2000)	Cross-sectional design Spearman correlations Regression analysis.	Participants who reported feeling punished and abandoned by God had significantly higher levels of anxiety This was also a significant predictor of depressed mood.	87%

*(Multidimensional measurement of religiousness/spirituality for use in health research: A report by the Feltzer institute on aging working group, Levin, 2003; Idler, 2003)

1.4. Results

1.4.1. Overview of reviewed studies

The quantitative studies measured the effects of religious coping strategies by investigating their association with particular outcome measures, i.e.

- Religiosity with mood (anxiety and depression) and/or psychosocial well being (Alferi et al., 1999; Culver et al., 2002; Gall et al., 2009; Herbert, Zdaniuk, Schulz & Scheier, 2009; Thunè-Boyle, Stygall, Keshtgar, Davidson & Newman, 2013).
- Religious coping strategies with hope (Ebright & Lyon, 2002; Stanton, Danoff-Burg & Huggins, 2002).
- Religiosity with quality of life (Pedersen, Christensen, Jensen & Zacharie, 2013).
- Religiosity with meaning making (Jim, Richardson, Golden-Kreutz & Andersen, 2006).
- Religiosity with positive growth (positive change or benefit finding) (Gall, Charbonneau & Florack, 2011)

The four qualitative studies explored the coping experiences of individuals newly diagnosed with breast cancer (Feher & Maly, 1999; Landmark, Strandmark & Wahl, 2001; Northouse, 1989; Taleghani et al., 2005).

Table 1.3 summarises the reviewed studies and states their quality score.

1.4.2. Key findings

For the purpose of this review, only results that were completed within six months post diagnosis or surgery were considered in each of the reviewed studies. The synthesis and interpretation of the data led to the emergence of three themes (see table 1.4). Each theme will be discussed in addition to the critical appraisal of the studies.

Table 1.4: Themes and the respective sub themes

Themes and the respective sub themes
<ul style="list-style-type: none">• Religion and its double pronged effect<ul style="list-style-type: none">○ Religion and its beneficial effects○ Prominent religious coping strategies utilised• The non significant role of religiosity• The negative effects of religiosity
<ul style="list-style-type: none">• Religious affiliation and conviction<ul style="list-style-type: none">• Affiliation to particular religious groups and cultural considerations• Religious conviction
<ul style="list-style-type: none">• Religiosity and demographic characteristics<ul style="list-style-type: none">• Ethnicity differences• Socio Economic status differences

1.4.3. Religion and its double pronged effect

The majority of the studies showed religious coping strategies positively helped people to cope with a diagnosis of breast cancer. However the effects of religious coping strategies were double pronged, as some studies showed religious coping strategies had a negative impact on those coping with a diagnosis of breast cancer. (Gall Charbonneau & Florack, 2011; Gall et al., 2009; Herbert et al., 2009; Landmark et al., 2001; Thunè-Boyle et al., 2013).

1.4.3.1. Religion and its beneficial effects

Religious coping strategies that were characterised as positive (e.g. religion to provide meaning, comfort and religious activities) helped individuals positively adjust and reduced distress levels in those newly diagnosed with breast cancer (Alferi et al., 1999; Culver et al., 2002; Ebright & Lyon, 2002; Feher & Maly, 1999; Gall et al., 2009; Jim et al., 2006; Landmark et al., 2001; Northouse, 1989; Pedersen et al., 2013; Stanton et al., 2002; Taleghani et al., 2005)

Gall et al. (2009) measured religious coping strategies using the RCOPE. The RCOPE allows one to measure different types of religious coping strategies (e.g. finding comfort in religion and using religion to make meaning) (Pargament et al., 2000). Gall et al. (2009) reported participants significantly increased their use of benevolent reappraisal (re-defining stressful events as part of God's plan) from pre-diagnosis to three months post surgery ($p=0.041$, $f(1,236)=4.23$) and

significantly increased their use of religious helping ($p=0.0001$) (using religion to help others), direction ($p=0.043$) (using religion to find new meaning) and focus ($p=0.003$) (using religious activities as distractions) from pre-diagnosis to one week pre-surgery. Religious helping predicted greater well-being one week pre-surgery. Gall et al. (2009) further compared the cancer group to a benign diagnosis group and found the cancer group significantly used all religious coping strategies except benevolent reappraisal more than the benign diagnosis group ($p= 0.005$). This suggests when an individual is faced with an uncontrollable life event such as a diagnosis of cancer they may be more inclined to use emotion focused coping strategies (Siegel et al., 2001). Gall et al. (2009) commented that a cancer diagnosis assessment may initiate a process of reflection on the meaning and purpose of life, potentially guided by religiosity. However, it is unclear if the participants also used other forms of coping and whether these influenced their use of the religious coping strategies, as only religious coping was measured. This study did however receive one of the highest quality scores². Alferi et al. (1999) measured religiosity by frequency of church attendance and prayer and the extent one turns to religion for comfort and considers the self as spiritual. Alferi et al. (1999) found the most used religious coping strategies by women with breast cancer were religious comfort (3.78-3.90 mean), followed by emotional support from church members (2.92-3.45 mean) and the least used strategy was talking to a priest or a minister (1.49-1.79 mean). These strategies were inversely related to

² The quality scores were calculated using an adapted version of the quality framework developed by Caldwell et al. (2011). The adaptations were informed by the quality framework developed by Kmet et al. (2004). See section 1.3.5

low mood, as measured by the Profile of Mood States (POMS). However, the benefits of religious coping were influenced by the participants' religious affiliation. Whilst this study received a relatively high quality score the sample only consisted of Hispanic women with a low Socio Economic Status (SES). Both studies were longitudinal and found using religious coping strategies in the first six months of diagnosis had longitudinal benefits.

The qualitative studies further supported these findings. Feher and Maly (1999) found participants used their religious faith to cope with a diagnosis of breast cancer, as it provided them with emotional support (companionship, comfort and strength from God), social support from church members and meaning in life (moral compass guided by God). Northouse (1989) and Taleghani et al. (2005) also found women highly used religious coping strategies when diagnosed with breast cancer. The qualitative studies varied in their level of quality as some of the studies had relatively small sample sizes, with little or no information on sample saturation.

The other studies in this review used more global measures of religiosity, making it unclear as to what type of religious coping strategies were utilised. Ebright and Lyon (2002) measured religious coping, by asking the participants (1-3 months post diagnosis) the extent their religious beliefs were helpful during treatment. They found self-esteem and 'helpfulness of religious beliefs' contributed significantly to the potential to positively cope and influence their breast cancer

experience ($p < 0.01$). However, this was influenced by the women's level of hope. Those with high levels of hope significantly positively appraised their cancer experience (higher scores on emotional coping and can influence their cancer experience) in comparison to those with low levels of hope. The relationship between hope and 'helpfulness of religious beliefs' was unclear, making it difficult to establish the extent to which variable (hope or religion) influenced positive coping. It was also difficult to determine if participants attributed helpfulness of religious beliefs to their treatment and/or to receiving their cancer diagnosis due to the religious measure used. This study received the lowest quality score of the quantitative studies. Nevertheless, this study suggests many factors can influence an individual's ability to potentially cope with a life impacting diagnosis.

Stanton et al. (2002) used the measure: COPE, which consisted of one religious coping item: 'finding comfort in religion'. This study found women with low levels of hope who turned to religion showed signs of positive adjustment (lower POMS scores and less fear of recurrence $p = 0.0001$) which was maintained one year post diagnosis. However, women with high levels of hope who turned to religion showed poor adjustment (higher fear of recurrence). This study received one of the highest quality scores and controlled for demographic variables that were associated with adjustment. This shows personal characteristics, such as hope can influence the beneficial effects of using religion to cope with a diagnosis of cancer (Stanton et al., 2002).

Both studies had small sample sizes and little information on the power of the analysis. The samples also consisted of predominately Caucasian women, limiting our understanding of hope and religious coping in different ethnic groups.

1.4.3.1.1. Prominent religious coping strategies utilised

The most prominent reason individuals used religion to cope was for comfort and emotional support (e.g. Alferi et al., 1999; Feher & Maly, 1999). The qualitative studies further explored this. Feher and Maly (1999) reported women felt a sense of companionship with their religious faith and felt God was taking care of them. The women further felt their faith offered them guidance, support and strength. This study received a relatively low quality score in comparison to the other qualitative studies.

Northouse (1989) found women drew strength from their religion, more so at 1-6 days post surgery, rather approximately 30 days post surgery, as this period was described as uncertain and fear of death. However, this qualitative study received the lowest quality score, as the data analysis and its credibility was minimally described, potentially affecting the reliability of the findings.

Landmark et al. (2001) found some women found religion enabled them to continue living when diagnosed with breast cancer. This study received the highest quality score of the qualitative studies. However, some of the quantitative studies only measured religiosity using a single religious item, such as 'finding

comfort from religion'. This may therefore be over represented in this review, making it difficult to determine how religiosity was used to cope with a diagnosis of cancer.

Two studies highlighted individuals used the social support aspect of religiosity to cope with their diagnosis of breast cancer. Feher and Maly (1999) found individuals used their church for social gatherings, praying with others and had good relationships with religious leaders. Taleghani et al. (2005) found Muslim women with breast cancer increasingly attended mosques and used imams. However, Pedersen et al. (2013) found Danish women with breast cancer from a secular society did not frequently attend church and appeared to prefer to practice their faith in a private non-organised manner. This suggests individuals from particular societies may use religion differently to cope.

Another way religion was used to cope with a diagnosis of cancer was to relinquish control to God. Gall et al. (2009) found participants who engaged in active surrender (willingly gave control to God) had lower levels of distress and better emotional well being ($p=0.0001$). It was suggested this was particularly helpful, at times when participants felt they had little control over their cancer (Gall et al., 2009).

Religious coping appeared to help individuals make sense of their diagnosis and provided meaning to their life. Jim et al. (2006) examined the relationship

between the coping strategies used when diagnosed with cancer on patients reported meaning of life. The individuals total meaning score was highly predicted by religious coping and less so by denial and avoidance coping strategies. Furthermore, those that used religious coping strategies at the time of their diagnosis scored highly on the spiritual domain of the meaning making measure (e.g. 'I find comfort in my faith and spiritual beliefs') two years post diagnosis. This study received a relatively high quality score and suggests using religious coping strategies at the time of diagnosis can influence how individuals apply meaning to their life. It also suggests how spirituality can be rooted in ones religious beliefs. Feher and Maly (1999) also found individuals newly diagnosed with breast cancer used religion to apply meaning to their life.

1.4.3.2. The non-significant role of religiosity

Some studies in this review found positive religious coping strategies were not always significantly associated with positive adjustment to the breast cancer diagnosis. Herbert et al. (2006) reported 76% of their sample used positive religious coping strategies. However, positive religious coping was not significantly associated with mental health scores, depressive symptoms and life satisfaction scores. Whilst this study received a relatively high quality score it had limited statistical power (effect size of 0.4). Thunè-Boyle et al. (2013) also found positive religious coping strategies were unable to predict a significant outcome in any of the variables (e.g. mood). This suggests religious coping strategies may not play

such an influential role when diagnosed with cancer or it could be a reflection of the outcome measures used.

1.4.3.3. The negative effects of religion

The religiosity measure: RCOPE was used in four studies and assesses negative and positive religious coping expressions. Negative religious expressions reflect feelings of abandonment, disappointment and anger towards God (Pargament et al., 2000). Thunè-Boyle et al. (2013) found women with breast cancer that scored highly on feeling punished and abandoned by God, were less likely to use acceptance ($t(153)=2.63$ $p=0.009$) and more likely to use denial coping strategies ($t(153)= -2.02$ $p=0.04$). This also significantly predicted higher levels of anxiety and depression ($t=2.713$, $p=0.007$). Even though this study received one of the highest quality scores, it was cross sectional and unable to infer causality; therefore being in a depressive state may have caused participants to appraise their diagnosis using a negative religious framework (Thunè-Boyle et al., 2013). Herbert et al. (2009) found similar results, as negative religious coping predicted worse overall mental health scores ($\beta=-3.06$ $p<0.05$), depressive symptoms ($\beta=2.05$, $p<0.01$) and less life satisfaction ($\beta=-2.0$, $p<0.01$). Gall et al. (2009) also found women who scored highly on feeling disappointed with God at a stressful time and asked God for a miracle had higher levels of distress from pre-diagnosis to one week pre-surgery ($f(3.74)=45,381$, $P=0.0001$).

Gall et al. (2011) reported negative rather than positive religious coping strongly and consistently related to positive growth. Interestingly, this study found those that felt disappointed with God ($P \leq 0.01$) and asked God for a miracle ($P \leq 0.01$) around the time of their diagnosis had greater levels of growth twelve months post diagnosis. This shows engaging in a religious struggle can have longitudinal benefits, as it may help individuals attribute meaning and find benefit in their cancer experience (Gall et al., 2011). This study received a relatively high quality score in comparison to the other quantitative studies. Landmark et al. (2009) also found a subset of the individuals newly diagnosed with breast cancer experienced religious doubt, whereby they felt religious beliefs had no importance during their illness.

Two studies reported that positive religious coping expressions (using religion for support and comfort) were associated with negative outcomes in a subset of their participant group (Alferi et al., 1999; Stanton et al., 2002).

1.4.4. Religious affiliation and conviction

1.4.4.1. Affiliation to religious groups.

Taleghani et al. (2005) found women from a Muslim faith and Eastern culture used similar religious coping strategies as women from Western countries, such as praying in places of worship, using clergy members and positively reframing the cancer diagnosis. However, the Muslim women appeared to describe their disease

as Gods will and a test that they would pass with pride, which was not evident in the studies conducted in Western countries. Whilst this shows religious beliefs may influence how and why religious coping strategies are used, this study had a relatively small sample ($n=19$) of Iranian women, which may not be more widely representative. However, this study received a relatively high quality score and stated the sample size was determined by data saturation (Taleghani et al., 2005). Alferi et al. (1999) also found women's religious beliefs influenced the benefits of using religious coping at the time of their diagnosis. Evangelical women, who had higher levels of religious involvement at the time of their diagnosis, had lower levels of distress ($p=0.003$). Catholic women who took comfort from their religion had higher albeit non-significant levels of distress at pre-surgery.

1.4.4.2. Religious conviction

Only one study measured participants' religious conviction. Pedersen et al. (2013) reported women that had a high level of faith in their religion were more likely to perceive their faith influenced their breast cancer illness and had a positive influence on their life, in relation to women that had some level of faith in their religion (47.6% vs. 3.4%). This shows the importance of considering the individuals level of religious conviction, as being affiliated with a religious faith does not mean religious coping strategies will have a beneficial effect (Pedersen et al., 2013). This study did however receive a low quality score, in comparison to the other quantitative studies and no information was provided on the reliability or validity of the religiosity measure.

1.4.5. Religiosity and demographic characteristics

1.4.5.1. Ethnicity differences

Only Culver et al. (2002) specifically looked at different ethnic group's use of coping strategies at different time points during the first year of a breast cancer diagnosis. They found that the African American ($p=0.05$) and Hispanic women ($p=0.001$) significantly used religious coping strategies more than the Non-Hispanic white women. The Non-Hispanic women in their sample used humour more than the Hispanic women ($p=0.001$). The African American and Hispanic women also reported less distress at pre and post surgery than the Non-Hispanic women. This study controlled for SES and suggested the differences were due to ethnicity. Although this study received a high quality score, only 6.2% of the sample were African American. The findings are therefore tentatively viewed and may not represent the particular ethnic groups. Culver et al. (2002) also used a single item to measure religious coping so it is unclear how religiosity was used to cope with the breast cancer diagnosis.

1.4.5.2. Socio Economic Status (SES) differences

SES is usually determined by one's educational level, employment status and income. A low SES is associated with lower levels of education, income and unemployment (American Psychological Association, 2007).

Alferi et al. (1999) specifically looked at Hispanic women with a very low SES, as 70% of the participant group earned less than \$8,000 a year. However, this study found the women's religious affiliation rather than their SES appeared to influence the benefits of using religious coping strategies when diagnosed with breast cancer.

The studies in this review provided limited data on the participants' SES. The studies that did comment on the SES reported that the participants were reflective of a higher SES group (Ebright & Lyon 2002; Herbert et al., 2009). This suggests religious coping strategies can be utilised by individuals from different SES groups, as religiosity is potentially accessible by all and not restricted by social, financial and educational barriers.

1.5. Discussion

This review aimed to critically review studies exploring the role of religiosity in individuals newly diagnosed with breast cancer. This review like others (Thunè-Boyle et al., 2006) has highlighted the complexity of religious coping strategies, as both positive and negative religious coping influenced psychological adjustment to a breast cancer diagnosis. However, the findings are tentatively discussed as there were a number of methodological limitations and many of the quantitative studies used religiosity measures that missed the complexity and versatility of religious coping.

Prior to discussing the findings, the conceptual confusion of religiosity will be commented upon, followed by the methodological limitations, future research directions and the clinical implications.

1.5.1 Conceptual confusion

Subtle nuances in the definition and conceptualisation of religiosity and its links with spirituality made it difficult to research religiosity as a separate entity. Firstly, some studies appeared to view religiosity and spirituality synonymously but measured religious coping separately and were therefore included in this review (e.g. Thunè-Boyle et al., 2013). However, studies that predominately measured spirituality or did not present the results of the religious and spiritual measures separately were not included in this review. Whilst this excluded potential studies, it limited the conceptual confusion between religiosity and spirituality. Secondly, some of the religious coping measures, had items that appeared to confuse spirituality and religiosity. For example, spiritual discontentment in the RCOPE was defined as disappointment with God (Pargament et al., 2000).

1.5.2. How religiosity was utilised

The most salient way religiosity helped individuals cope was by providing comfort and emotional support (Alferi et al., 1999; Culver et al., 2002; Taleghani et al., 2005). This suggests individuals who use positive religious coping may have a

positive relationship with God and therefore a potentially secure attachment with God at a particularly stressful time (Kirkpatrick, 2001). A secure attachment provides a source of comfort, enabling people to feel safe (Prior & Glaser, 2006). Religious coping also appeared to help individuals cope by finding new meaning in their life (Gall et al., 2009; Feher & Maly, 1999; Jim et al., 2006). Siegel et al. (2001) reported individuals who question and attempt to find meaning of their life-threatening event often search for this within a religious context.

Some of the studies measured religious coping at different time points throughout the first years of a cancer diagnosis. They found individuals around the time of their diagnosis (pre-surgery/weeks after surgery) felt they had little control of their situation and feared death. At these times individuals significantly used religious coping strategies (Gall et al., 2009; Northouse, 1989). This suggests when individuals are faced with a traumatic uncontrollable stressful event, emotion focused coping strategies are used, as the individual attempts to alter their relationship with the stressor (Lazarus, 1993). This is in line with previous research (Siegel et al., 2001; Tix & Frazier, 1998).

However, positive religious coping strategies were also associated with poor adjustment to the cancer diagnosis. Stanton et al. (2002) found women with high levels of hope who used religious coping strategies showed poor adjustment to their cancer diagnosis. It is possible that women high in hope may strive to overcome obstacles in their life and therefore found religion did not provide them

with the vicarious control they required to positively cope with a highly stressful event (Stanton et al., 2002). However, this study used a generic coping measure. It is therefore unclear what types of religious coping were used by the women and whether women with high or low levels of hope used different types of religious coping strategies.

1.5.3. Negative effects of religiosity

Individuals who engaged in negative religious coping (disappointed, angry and/or felt abandoned by God) when diagnosed with breast cancer had greater levels of distress, depressive/anxiety symptoms and less life satisfaction (Gall et al., 2009; Herbert et al., 2009; Thunè-Boyle et al., 2013). These findings were from quantitative studies that received high quality scores. Pargament, Smith, Koenig and Perez (1998) reported negative religious coping patterns may be associated with a less secure relationship with God and an ominous view of the world. Koenig (2013) reported individuals who have a chronic illness and feel that their pain is resistant to prayer may conclude that God is punishing them. The individual may therefore become angry at God and challenge God's ability to make a difference. This could potentially make individuals lose faith in God's existence (Koenig, 2013).

It is important to note, that the majority of the studies only measured positive religious coping strategies, which potentially may be over represented in this

review. The studies which looked at positive and negative religious coping, predominately found consistent and significant results with the negative religious coping, in comparison to the positive religious coping. Some of the positive religious coping findings were either non-significant or contradictory, as some studies showed positive religious coping was not always associated with positive adjustment to the breast cancer diagnosis (Stanton et al., 2002). This highlights the complexity of positive religious coping strategies and the challenges for empirical research.

1.5.4. The influence of different factors on religiosity

Factors such as an individual's religious faith, culture, religious conviction and ethnicity influenced the role of religiosity when coping with a diagnosis of breast cancer. Individuals from a Muslim faith and Eastern culture coped with their cancer diagnosis mainly using their religion (Taleghani et al., 2005). Alferi et al. (1999) reported women of the Catholic faith, in comparison to women from an Evangelical faith, did not benefit from using religious coping strategies. This may be related to the religious ideologies, as Catholicism is associated with confession and judgement, whereas Protestants tend to emphasise acceptance (Alferi et al., 1999). In the Muslim faith, negative religious expressions would be going against God's will (Astrow, Mattson, Ponet & White, 2005). Furthermore religion may be a more salient feature of Eastern cultures and therefore potentially highly used to cope with a cancer diagnosis (Al-Azri, Al-Awisi & Al-Moundhri, 2009).

Culver et al. (2002) found participants ethnicity influenced how they coped with their cancer diagnosis. However, the different ethnicity groups were unequally represented as the majority of the sample was made up of Non-Hispanic women. Nevertheless, these studies highlight the importance to train professionals to be sensitive to the religious needs of individuals from different cultures and faiths (National Institute for Health and Clinical Excellence [NICE], 2004).

1.5.5. Methodological limitations

The methodological limitations have been considered throughout this review. However a number of themes arose.

A number of the studies in this review did not score well on the 'population sample' quality criterion (see appendix 5). Many studies had small sample sizes, with little or no information on the power of the analysis and effect size. The majority of the studies used correlation analyses, which makes it difficult to infer causality. Additionally, religious coping was not always assessed alongside other coping methods. The influence of other coping methods on religious coping and vice versa is therefore unclear. The population sample of this review was exclusively women the majority of whom affiliated themselves with the Catholic

or Protestant religion³. The findings are therefore difficult to extrapolate to other religious faiths or cultures.

Some of the studies in this review used generic coping measures that only included a single nonspecific item on religious coping (e.g. Stanton et al., 2002). Furthermore the studies which focused on religious coping used sub-scaled versions of the religious coping measure (e.g. Gall et al., 2009) and therefore were unable to capture the full range of religious coping strategies, consequently limiting our understanding of religious coping.

Only studies published in peer reviewed journals and written in the English language were considered for this review. Whilst this ensured a minimal level of quality, it may have potentially excluded relevant research and introduced a publication bias. Considering 'grey' research may reduce the effects of publication bias.

Eight (57%) of the studies were conducted in the USA in comparison to one in the UK. Census surveys show the USA population considerably identify themselves with a religion more than the UK population (British Humanist Association, 2015; Kosmin & Keysar, 2009). The results may therefore be potentially influenced by the research participants' level of religious conviction. Further research conducted

³ This information was taken from the studies included in this review where religious preference of the participant sample was stated.

in the UK focusing on religious conviction levels is recommended to further explore the role of religious coping in the UK.

In the study by Landmark et al. (2001) two of the participants were seen twelve months post diagnosis which means the data was retrospective and potentially influenced by other cancer related experiences. However, this study was not excluded as some of the participants were seen within 6 months of receiving their cancer diagnosis and the interview questions specifically explored their experiences of being newly diagnosed with breast cancer.

This review specifically explored the role of religiosity six months post diagnosis or surgery. However, there may have potentially been a delay for surgery following the breast cancer diagnosis. Although, surgery is the most common form of treatment following a breast cancer diagnosis (Cancer Research UK, 2015)

1.5.6. Future research directions

Whilst tentative conclusions can be drawn from this developing research, there are a number of areas that require future research attention:

1. This review focused on individuals diagnosed with breast cancer; whilst this may be reflective of the worldwide statistics regarding the most diagnosed cancer, it tells us little about how individuals cope with other

forms of cancer. Different cancer sites have varying forms of treatments, with their own side effects and pain levels (American Cancer Society, 2014; Cancer Research UK, 2014).

2. The mean age of the participants in the studies in this review was 55.3⁴ years, which makes it unclear how other age cohorts' may use religious coping when diagnosed with a life impacting illness.
3. This review was unable to comment on how males may use religiosity to cope with a diagnosis of cancer. Studies have shown males are less likely to benefit from religious coping and are more likely to use other forms of emotion focused coping (Gall, 2004).
4. As previously noted, religiosity was measured crudely and some of the outcome measures that assessed psychological adjustment to a cancer diagnosis lacked adequate levels of reliability and validity (e.g. Ebright & Lyon, 2002). Future research may benefit from greater qualitative research, which could potentially fully explore the role of religiosity when coping with a life impacting illness (Chittem, 2014; Lavery & O'Hea, 2010)
5. The majority of the studies in this review were conducted in Western countries, limiting out understanding about any differences in religious coping when diagnosed with cancer in different cultures.
6. Individuals appear to benefit from religious coping by viewing God as a secure attachment figure (Kirkpatrick, 2001). Exploring an individual's

⁴ These figures were taken from the studies in this review which stated the mean age.

attachment style and their use of religiosity when coping with a life impacting diagnosis is recommended.

1.5.7. Clinical implications

Despite the limitations, this review shows religious coping strategies can significantly help some individuals cope with a breast cancer diagnosis. Individuals seem to use a diverse range of religious coping strategies that appear to serve different functions. The NICE (2004) guidelines on cancer services state that an individual should be offered a holistic assessment that enquires about their religious/spiritual needs at different time points throughout their cancer journey. The assessment should include how people make sense of their situation, what they draw upon for strength and support and whether they find their spiritual/religious strategies helpful. The guidelines state a cancer diagnosis is a time of uncertainty whereby individuals may re-evaluate their religious/spiritual beliefs and staff should help facilitate this process if appropriate. This would therefore allow professionals to enquire about the individual's use of religion, as a negative religious appraisal of their cancer diagnosis can hinder positive coping (Gall et al., 2009). Professionals could therefore potentially direct individuals to religious clergy members to resolve their religious struggle and promote the use of positive religious coping strategies (Gall et al., 2009; Herbert et al., 2009). Gall et al. (2011) further reported individuals who used negative religious coping in the first six months of their cancer diagnosis had greater levels of positive growth

twelve months post diagnosis, which may have been due to the resolution of their religious struggle.

Schofield et al. (2003) reported that a patient centred consultation, which is where professionals elicit and appropriately respond to the patients needs are most effective when communicating the cancer diagnosis and treatment options. This further supports the value of assessing religious/spiritual beliefs at the time of diagnosis. However, spiritual/religious support in services is frequently unrecognised and staff may feel reluctant to discuss such issues (NICE, 2004). Hill and Pargament (2003) reported that professionals do not seem to refer to clergy or religious groups, even though research suggests religious strategies can play an important role when coping with a life threatening illness. This review supports the importance to assess and address positive and negative religious coping in those who receive a life impacting diagnosis.

1.5.8. Conclusion

Religiosity has been difficult to conceptualise and as a result difficult to measure. This has led to crude measures of religiosity which are unable to capture the quality of religious coping when faced with a life impacting diagnosis. The findings of this review are constrained by methodological limitations and should be tentatively viewed. Despite this, the review showed the diverse way religiosity is used and that positive and negative religious coping strategies can help or hinder

individuals coping with a breast cancer diagnosis. This highlights the need for professionals to enquire about religious coping strategies in individuals newly diagnosed with a life impacting illness.

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Chapter 2: Empirical paper

'I just knew he was different and I didn't know what': A
qualitative study exploring parents' experiences of raising
their child who was diagnosed with Asperger Syndrome in
adulthood

In preparation for submission to Research in Autism
Spectrum Disorders Journal (see appendix 2 for author
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2.1 Abstract

Asperger Syndrome (AS) is a lifelong developmental condition and usually diagnosed at a later age than autism. Individuals with AS may therefore be more dependent on parents for support. However, there is limited research on parents' experiences of caring for their adult offspring with AS, especially when diagnosed in adulthood. This study aims to explore parents' experiences of raising their child diagnosed with AS in adulthood. Semi-structured interviews were conducted with eight parents. The transcripts were analysed using Interpretative Phenomenological Analysis. Three themes emerged from the data: *'Parenting the unknown'*, *'Services fumbling in the dark'* and *'Fear of the future'*. All themes were heavily influenced by the lack of understanding, awareness and recognition of AS amongst professionals and the parents interviewed. Parents also expressed concerns regarding whether service provisions would be able to meet their offspring's needs when they could no longer care for them. The parents' accounts highlighted the importance of educating and promoting an awareness of AS amongst different professional groups. The clinical implications include the need for tailored service provision for adults with AS, which incorporates parents in the planning of their offspring's future.

Key words: Parents experiences, late diagnosis, Asperger Syndrome,
Interpretative Phenomenological Analysis

2.2 Introduction

Asperger Syndrome (AS) was first documented by Hans Asperger in 1944, when he observed children displaying difficulties in social integration, unusual speech content and special interests which, he named 'Autistic Psychopathology' (Asperger, 1944 translated by Frith, 1991). Asperger's work became more accessible to the English speaking psychological and medical profession when it was described by Wing (1981). Wing (1981) commented the term 'Autistic Psychopathology' could be inappropriately associated with sociopathic behaviour and therefore used the term AS. It was felt the observations made by Hans Asperger were in line with Kanner's work in 1943 on infantile autism, which led to AS becoming part of the autism spectrum (Wing, 1981, 1991). The autism spectrum is made up of a broad range of developmental disorders which range from severe learning disability to high functioning autism and AS (Wing, 1981; Wing & Gould, 1979). Autism Spectrum Disorders (ASD) can be characterised by difficulties in three main areas: social interaction, social communication and imagination, and repetitive pattern of interests and activities, known as the triad of impairments (Wing, 1991, 2005; Wing & Gould 1979).

For well over a decade AS was recognised as a formal diagnostic category in the Diagnostic Statistical Manual of mental disorders fourth edition (DSM-IV) (American Psychiatric Association [APA], 1994). However, due to a number of diagnostic issues (see below) the Diagnostic Statistical Manual of mental disorders

fifth edition (DSM-5) has removed AS and other autism diagnostic categories and replaced them with one overarching diagnosis called Autism Spectrum Disorder. This would therefore be given to those who previously would have been diagnosed with AS (APA, 2013a). The changes in the DSM-5 were intended to improve the validity and reliability of an ASD diagnosis (McGuinness & Johnson, 2013). However, the International Classification of Diseases version 10 (ICD-10) still recognises AS as a separate diagnostic category (World Health Organization [WHO], 1992) and therefore the diagnostic issues surrounding AS are still present.

2.2.1 Diagnosis issues

There has been some controversy over the years regarding the association of AS with autism (Sharma, Woolfson & Hunter, 2011; Wing, 1991). Consequently, AS lacks a consensual operational definition (Klin, Pauls, Schultz & Volkmar, 2005) and has been diagnostically defined by many individuals using their own observational data of clinical cases (Gillberg, 1991; Wing, 1981). The DSM-5 and ICD-10 both use the core impairments of autism as the basis of their diagnostic criteria (APA, 2013b; WHO, 1992). However, many elements of the core impairments of autism have not been standardised and require observational judgements (Tantum & Gurgis, 2009). The language difficulties associated with AS have also been the subject of debate. The ICD-10 diagnostic criteria for AS states a lack of a clinically significant language delay in spoken or receptive language (WHO, 1992). However, Gillberg (1991) reported that a language delay may exist

in the form of semantic, pragmatic and comprehension difficulties. This means diagnosing AS is difficult and greater research is needed to clarify the qualitative differences between autism and AS (Ghaziuddin, 2008). Kopra, Wendt, Wendt and Paavonen (2008) reported poor agreement between the different diagnostic criteria for AS can make it difficult to compare studies. This has also effected the reported prevalence rates of AS. In a review of the epidemiological research on AS, the prevalence rates ranged from 0.8 to 43.4 per 10,000. The variance within this range was reported to be due to the lack of agreement between the different diagnostic criteria used (Fombonne & Tidmarsh, 2003). Additionally some researchers believe that AS and autism share the same fundamental symptoms differing only in their degree of severity (Ozonoff, South & Miller, 2000). Cashin (2006) further suggested that the different diagnostic categories describing the range of ASDs, can confuse parents and make the diagnostic process unreliable.

Research shows AS tends to be diagnosed at a later age than autism and parents usually see more professionals en route to their child's diagnosis (Goin-Kochel, Mackintosh & Myers, 2006). AS is thought to be difficult to detect in childhood because of the absence of a language delay and social impairments are usually more apparent at school age; therefore usually diagnosed at a later age (Siegel, 1996). Furthermore, some accompanying behaviour such as motor clumsiness is difficult to characterise in two to three year olds further complicating early diagnosis of AS (McConachie, Le Couteur & Honey, 2005). Rosenberg, Daniels, Law, Law and Kaufman (2009) looked at trends in ASD diagnoses from 1994 to

2007 and found the age at which individuals were diagnosed with AS increased over time. Interestingly, the majority of AS diagnoses were made by a psychiatrist or psychologist indicating they may have initially been referred for reasons other than a diagnostic assessment. This suggests individuals with AS may have been misclassified when initially assessed (Rosenberg et al., 2009). However, Tantum (1991) found a considerable amount of adults with AS meet criteria for psychiatric disorders other than developmental disorders. Additionally, AS may be diagnosed later in life because the individuals' difficulties may have been masked by their intellectual abilities (Portway & Johnson, 2003).

2.2.2 The impact of a diagnosis of AS

A diagnosis of AS can act as a gateway to specialist services and support (Molloy & Vasil, 2004; Seigel, 1996) and is believed to be the first and most important step to its management (Tantum & Girgis, 2009).

2.2.2.1 The impact on the individual

Molloy and Vasil (2004) interviewed adolescents with AS and found the diagnosis provided them with an understanding of their difficulties. However, individuals did not share their diagnosis with others, fearing it could potentially damage the relationship or lead to bullying. The individuals also found it difficult to integrate the diagnosis into their identity whilst distinguishing it from their personality.

Punshon, Skirrow and Murphy (2009) interviewed adults diagnosed with AS in adulthood and found a delay in receiving a diagnosis of AS led to the individuals feeling misunderstood and blamed for their difficulties. They felt different from others, with no explanation as to why, and lacked trust in services. However, the diagnosis did provide them with a sense of belonging to a group. Portway and Johnson (2003) also found adults with AS identified with 'not fitting in' as a core theme to describe their life experience.

2.2.2.2 The impact on parents

Moyes (2003) found the majority of parents move through four stages of emotion when adjusting to their child's AS diagnosis. Firstly parents may feel doubt; even though they may have suspected their child was different, their concerns may have been dismissed by professionals. However, some parents found the diagnosis validated their concerns. Secondly, despair if they found it difficult to find support. Thirdly anger, potentially towards God and health professionals, as they may have questioned 'why them?' Lastly fear of the future.

There is considerably more research investigating parent's experiences of having a child diagnosed with AS in childhood, in comparison to relatively little research on having a child diagnosed in adolescence or adulthood. Epstien, Saltzman-Benaiah, O'Hare, Goll and Tuck, (2008) found parents of children with AS experienced elevated levels of stress, which was primarily due to greater levels of executive

functioning and sensory difficulties within their child. Mori, Ujiie, Smith and Howlin, (2009) found higher stress levels in Japanese parents of children with AS in comparison to parents of children with autism. This was attributed to the child's basic behaviour, temperament and parental perceptions. Mugno, Ruta, D'Arrigo and Mazzone (2007) reported parents of children with AS had lower quality of life scores, which was due to their child being bullied and rejected at school, the strain of not understanding their child and the difficulties obtaining a correct diagnosis. Chell (2006) interviewed parents of children diagnosed with AS and found a major theme was a lack of understanding and recognition of AS amongst professionals and wider society. The parents therefore reported feeling isolated and experienced difficulties getting their child diagnosed. The parents reported the diagnosis validated and confirmed their instincts, provided them with relief and an understanding of their child. However, for some parents the diagnosis was also associated with grief and fear (Chell, 2006). Lastly Meirsschaut, Roeyers and Warreyn (2010) found mothers of children with AS reported having to adjust their careers, had little time for personal activities and responded less to their other children's needs. This research highlights the stress parents may experience raising a child with AS and the potential difficulties obtaining a diagnosis of AS for their child.

Research has shown parents cope with their child receiving a diagnosis of AS by positively making sense of the diagnosis using spirituality and reframing it as a difference rather than a disorder (Samios, Pakenham & Sofronoff, 2008). Samios,

Pakenham and Sofronoff (2009) reported parents may positively adjust to their child's AS diagnosis by finding benefits, such as meeting new people and personal growth (being more patient, tolerant and open minded). The biggest benefit was a greater understanding of their child although this was associated with higher levels of anxiety, as more awareness may raise anxieties and vulnerabilities within the parents (Samios et al., 2009). Molloy and Vasil (2004) reported an AS diagnosis provided parents with a narrative to understand and make sense of their child's behaviour.

To date only one study has reported on the experiences of parents caring for their adult offspring with AS, diagnosed aged 14 to 35 years. This study found parents experienced their offsprings' difficulties as hidden from others. This meant their supportive role was also hidden, which led to feelings of isolation. Interestingly, the parents did not appear to find their care giving role a strain, even though they reported years of stress. However, this study had a relatively small sample group, and all offspring were male⁵ limiting the generalisability of the findings (Griffith, Totsika, Nash, Jones & Hastings, 2012). Portway and Johnson (2003) retrospectively explored the experiences of adults with AS and their parents. They found parents were highly distressed when they felt their child did not 'fit in' and were therefore misunderstood, bullied and ostracised.

⁵ The male to female ratio for individuals diagnosed with AS has been reported to be 4:1 (Ehlers & Gillberg, 1993). However the recognition of females diagnosed with ASD is increasingly growing (National Autistic Society, 2015).

2.2.3 Rationale

With the growing recognition and the difficulties diagnosing AS, many individuals can remain undiagnosed until adulthood (Prayson & Franco, 2012). Individuals' experiences of being diagnosed with AS has increasingly been researched (e.g. Jackson, 2002; Punshon et al., 2009). However, parents' experiences of their child receiving a late diagnosis (in adulthood) have yet to be researched. Research has shown a diagnosis of AS provides parents with a framework to make sense of and understand their child's behaviour (Chell, 2006; Malloy & Vasil, 2004). Furthermore, early recognition and diagnosis of AS can reduce risks such as high levels of anxiety and dependency on parents (Portway & Johnson, 2005).

This study aims to build on the existing knowledge of parents' experiences of having an adult offspring with AS, specifically exploring parents' experiences of raising their child who was diagnosed in adulthood. It is hoped this study will deepen our understanding of parents' experiences and help inform how service provisions can support the individual and their family. The guidelines on adults with autism published by the National Institute of Health and Clinical Excellence (NICE) state that we should work collaboratively with families, and provide them with emotional support, support in their caring role and the planning of their child's future (NICE, 2012)

2.2.3.1 Aims and research questions

This study aims to explore the experiences of parents of raising their child who received a diagnosis of AS in adulthood.

The key question is:

1. How did parents cope raising a child without an AS diagnosis?

Specifically, the researcher aims to explore the following areas:

1. How did parents cope without the support of services for people with AS?
2. What (if any) stressors did parents encounter raising their child?
3. What services do parents think should be in place to address their needs?

2.3 Method

2.3.1 Design

To capture the personal experiences of parents the qualitative approach: Interpretative Phenomenological Analysis (IPA) was chosen. IPA explores an individual's personal account of a particular object or event and allows the researcher to attempt to understand the participants' experiences and

perceptions from their view point (Smith, Flower & Larkin, 2009). IPA studies conducted in health care settings can offer an understanding of the participant's social reality of a particular condition or situation, hence potentially informing clinical practice (Biggerstaff & Tompson, 2008).

2.3.2 Subjective position

IPA inherently involves the researcher making interpretative claims on the participants' subjective experiences (Smith et al., 2009). Larkin, Watts and Clifton (2006) report no matter how desirable; the researcher is unable to remove their thoughts, experiences and meaning systems from the world. The researcher therefore needs to be reflective to allow the data to represent the views of the participants.

The researcher has had previous experience of working with adults who received a diagnosis of AS. From this, the researcher developed an interest in parents' experiences of their child receiving a late diagnosis of AS. However, the researcher was unable to meet with parents at that time and therefore had minimal preconceived ideas of what the interviews may hold. Any assumptions held by the researcher were discussed during the bracketing interview. A bracketing interview allows the researcher to become more aware of and explore their preconceptions and personal feelings that could subjectively bias the interpretation of the results and interview process (Ahern, 1999).

2.3.3 Epistemological position

The researcher has always been interested and influenced by humanistic psychology, mainly the person centred approach. This may have encouraged the researcher to be open to new discoveries, tolerate uncertainty and be able to focus on particular incidents as well as considering the parents experiences holistically (Wilkins, 2010).

At the time of data analysis, the researcher was working in a psychodynamic psychotherapy team, which may have potentially influenced the researcher's position and made them more attuned to symbolic references within the data. This was further explored with the supervision team, to ensure the data was coded with minimal bias.

The researcher reflected on the impact of a 'Psychologist' interviewing the participants and the effect this may have had on them. The researcher was mindful of this throughout the interview process.

2.3.4 Participants

The population of interest for this study were parents whose child was diagnosed with AS in adulthood. See table 2.1 for the inclusion and exclusion criteria.

Table 2.1: Participant inclusion and exclusion criteria

Inclusion criteria
<ul style="list-style-type: none">• The participants' offspring had to be diagnosed with AS after their 18th birthday by a qualified health professional or diagnostic team.• The participant was able to give their time to be interviewed by the main researcher.• The participant was able to provide informed consent.• The participant could speak and understand the English language.
Exclusion criteria
<ul style="list-style-type: none">• The participants' offspring was diagnosed within the last 6 months.

In line with IPA, the sample was as homogeneous as practically possible (Smith et al., 2009). Eight participants were recruited: six mothers and two fathers. Smith (2003) and Smith et al. (2009) suggest between three and six participants for a reasonable IPA study sample size, as IPA concerns itself with the interpretation of in depth individual experiences. The eight interviews should therefore ensure a sufficient amount of breadth and depth of personal experience accounts.

Table 2.2 provides a summary of the participant information. Pseudonyms were given to all participants. The length of the interviews ranged from 23 to 56 minutes (median and mean = 45 minutes). Lilly and Mark were husband and wife and raised the same child. Mary's offspring with AS was present during the interview.

Table 2.2: Participant information.

Participant Pseudonym	Age offspring was diagnosed with AS (years)	Age of offspring at interview (years)	Gender of offspring
Rose	20	33	Male
Laura	19	23	Male
Mark	36	38	Female
Lilly	36	38	Female
Mary	25	33	Male
James	23	25	Female
Celia	37	43	Male
Beth	37	41	Male
Median	30.5	35.5	
Mean	29.1	34.2	
Range	19 – 37	23-43	

2.3.5 Recruitment

All participants were recruited from a voluntary, charity funded support group for adults with AS called Aspie based in the Midlands. The researcher attended Aspie to meet group organisers and distribute posters briefly detailing the nature of the study and contact details of the main researcher (see appendix 8). Interested parties were able to directly contact the researcher to arrange an interview time.

2.3.6 Ethics

This research was carried out following the ethical recommendations as set by the British Psychological Society (BPS, 2009; 2010). Ethical approval for this study was sought and given by the ethics committee at Coventry University (see appendix 9). The ethics committee were further informed of recruiting participants from Aspie, (via a gatekeeper letter) which was also ethically approved (see appendix 10).

2.3.7 Materials

An interview schedule (see appendix 11) was created in order to facilitate the semi-structured interviews. The researcher developed the questions in consultation with clinicians who had experience of diagnosing adults with AS and from the literature exploring how individuals and their parents have coped with an AS diagnosis (Chell, 2006; Portway & Johnson, 2003, 2005; Punshon et al., 2009). The interview schedule consisted of open ended questions, avoided jargon and was used flexibly to effectively elicit the individual's experiences (Smith, 2003).

2.3.8 Procedure

The researcher carried out the interviews in a private comfortable room at the Aspie organisation.

Before each interview, the researcher went through the participant information sheet (see appendix 12) to ensure all points were understood and to answer any questions. The participant was then asked to sign the informed consent sheet (see appendix 13). The participants were informed that the interview was flexible and centred on their experiences. After the interview, the participant was given the debrief sheet (see appendix 14) and the opportunity to discuss the interview.

All interviews were recorded on a digital audio recorder and stored on a password protected computer. All recordings were transcribed verbatim and personal identifiable information was anonymised.

2.3.9 Data Analysis

The data was analysed (see appendix 15) following the guidance of Smith et al. (2009). These steps allowed the researcher to move from a descriptive to an interpretative phase, whilst encouraging a reflective engagement with the participant's experience. After completing steps 1 and 2 (see appendix 16). The themes of each participant were organised and similar themes were clustered to

identify super-ordinate themes (see appendix 17). The researcher then developed the sub themes and their respective super-ordinate titles (see appendix 18).

2.3.10 Credibility of the analysis

The importance of assessing the quality and validity of qualitative research is highly recognised (Smith et al., 2009). Yardley (2000) developed criteria to assess the quality of qualitative research, which consists of four categories: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance.

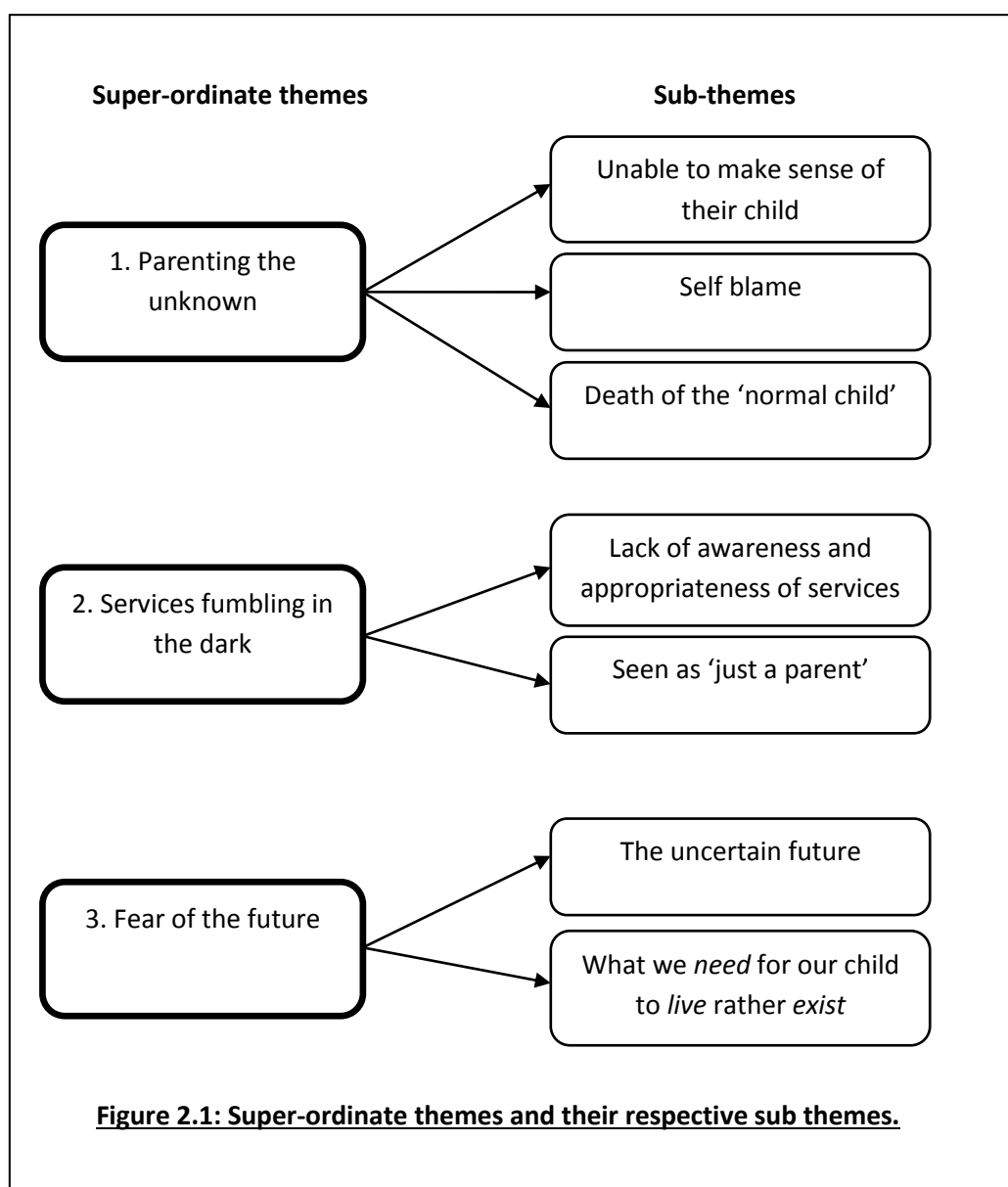
The researcher aimed to meet these throughout the data collection and analysis phase. The researcher clearly and concisely reported all data collection and analysis steps to ensure full replication. To ensure reliability and validity of the data analysis, the emergent themes alongside the participant extracts were discussed with the supervision team. Additionally, an interview was coded by a peer familiar with IPA, which was compared with the main researcher's coding to check for any significant discrepancies. To ensure the analysis was completed with minimal bias the researcher kept a reflective journal, and completed a bracketing interview. A bracketing interview ensures some validity of the data collection and analysis (Ahern, 1999).

2.4 Results

A pervasive theme present throughout all the interview data sets was the lack of awareness, recognition and education of AS amongst the professionals and parents, as illustrated by Rose:

'I just knew he was different and I didn't know what, didn't know how and I didn't know why' (225-227)*

This has shaped the following three super-ordinate themes (see figure 1.1.). Each theme will now be explored and represented by a single participant extract (*represent line numbers). See appendix 19 for further participant extracts.



2.4.1 Super-ordinate theme 1: 'Parenting the unknown'

All the parents in this study conveyed a sense that they did not understand their child and therefore felt they were 'parenting the unknown'. Many of the parents appeared to feel guilty and blamed themselves for potentially contributing to

their child's difficulties and did not do enough to pursue an earlier diagnosis. Parallel to this, some of the parents minimised their child's difficulties and felt they would grow out of them. They therefore appeared to hold on to the belief that their child was 'normal' and did not fully acknowledge their limitations.

2.4.1.1 Unable to make sense of their child's difficulties

The parents described having a strong awareness that their child was different to other children but unable to understand why, which they found frustrating and isolating. The parents appeared to struggle to make sense of why their child excelled in some areas but struggled in others. Parents also discussed not knowing how to best manage some situations because of their lack of understanding.

'We had always knew there was something wrong' (Beth, 145-146)

'Frustrating, straight away. Yes frustrating....I would also say isolating' (Mary, 4-5)

Interestingly, when attempting to understand their child's difficulties, some of the parents ruled out the possibility of autism because they appeared to be unaware of the range of ASD presentations.

'I only knew about conventional classic autism' (Rose, 106)

Beth and Celia attributed their child's difficulties to birth trauma and substance misuse, highlighting the extent to which parents went, to understand their child.

'I always thought he had possibly got minimal brain damage' (Beth, 147-149)

'Wondered whether it was drugs because of the way he acted' (Celia, 122-123)

The fathers in this sample however, did not appear to acknowledge their child was different and saw their behaviour as a part of them rather than a cause for concern.

'We see certain oddities going right back. But if it's your first child you know that's your child' (James, 12-14)

Some of the parents appeared to perceive others as judgemental, which was enhanced by parents viewing their child's difficulties as hidden from others.

'Felt that the other parents would look at him and whether I felt at the time they were making judgements about me as a mother' (Mary, 14-17)

Even though the majority of the parents discussed the difficulties of raising their child they also spoke very lovingly of them and proud of their achievements despite their difficulties.

'I mean we didn't get anywhere [with health services]....I actually admire my son because...he showed great strength and courage' (Mary, 233-237)

2.4.1.2 Self blame

Many of the parents spoke about not being a good enough parent, and consequently appeared to blame themselves and feel guilt and shame. They felt that they should have done more to pursue their instinct and therefore appeared to feel that they had let their child down.

'Maybe I'm a bad mother but I didn't go looking. I didn't know how to I didn't know what to go looking for' (Rose, 279-281)

Some of the parents appeared to question whether their parenting contributed to their child's difficulties. This appeared to create anxiety and reinforce the idea that they were not good enough. Furthermore, this appeared to be exacerbated by the lack of support and recognition of their child's difficulties from outside services (mainly school).

'Danger that you can get to that place as a parent beating yourself up for getting it wrong and that doesn't do any good to anybody' (James, 307-309)

Many of the parents felt relieved when their offspring received an AS diagnosis. This appeared to reduce the guilt and make them feel less responsible for their child's difficulties. Furthermore, it helped them make sense of the difficulties they encountered raising their child.

'I could float up in the air. Like a great burden had been lifted at last....and thankful, hugely relieved' (Mary, 246-247)

Rose and Mary commented that they experienced mental health difficulties caring for their child. However, only Beth spoke about not being able to express her stress, to potentially stay strong for her family.

'I was depressed...for a period I was suicidal' (Rose, 502-503)

'I never voiced it, I never said anything to anybody' (Beth, 165)

The parents also discussed their protective factors. James and Mary held strong religious beliefs, which they felt significantly helped them cope with the difficulties of raising their child.

'We are very strong Christians if it wasn't for that...it would have destroyed the whole thing. That was about all that...kept the family together' (James, 96-98)

Laura, Lilly and Celia found their partners support kept them going and made them feel they were doing a good enough parenting job. Beth coped by sharing her problems with others.

'My husband and I...have a very loving relationship...we always say thank goodness he was born into our family...we have stayed married for 30 years and I'm sure that's got to be helpful' (Laura, 133-136)

2.4.1.3 Death of the 'normal' child

Many of the parents appeared to minimise their child's difficulties and felt they would grow out of them. They also did not see them as a cause for concern because they were functioning well in other areas.

'Speech we weren't too worried about because my husband had been slow to speak as a child....you just put it down to he'll get there. He is a boy he is lazy' (Beth, 350-354)

Upon their child receiving a diagnosis, many of the parents in this study commented feeling sad. The parents appeared to grieve the death of having a 'normal child' and fantasised about what their child's life could have been like without AS.

'Why shouldn't she be fit and healthy. Not a normal child, what I perceived to be a normal child' (Mark, 104-106)

Only James acknowledged that his daughter could potentially have a fulfilling but different future.

'Because your child sees the world a little bit different...doesn't mean that they will never have a future' (456-458)

2.4.2 Super-ordinate theme 2: 'Services fumbling in the dark'

The majority of the parents in this study described feeling let down by services. They appeared to describe professionals as having little awareness of AS. This meant the AS was unrecognised and consequently the parents felt their child was offered inappropriate interventions. Parents described their interactions with services as mixed. The majority of the parents felt their concerns were dismissed because they were 'just the parent'. When parents felt their concerns were acknowledged they appeared to be hugely grateful.

2.4.2.1 Lack of awareness and appropriateness of services

The majority of the parents in this study described services they engaged with, lacked an awareness and understanding of AS, which affected the intervention or service that was offered. Parents spoke about their child having to fit into services that did not suit their needs and seemed incongruent to their child's level of difficulties. However, the parents in this study did not appear to question the support they received and seemed grateful that their child's difficulties were being recognised.

'Did not feel natural [attending child development centre]...I was pleased when he was discharged...it was somewhat distressing taking my son there...areas of his development that did need help so I let him go there but I wasn't very happy about it' (Laura, 46-49)

Some parents in this study appeared to feel that services were not interested in their child's behavioural difficulties because they were unable to explain them or offer support. These experiences, as well as feeling services had let their child down, appeared to make some parents feel resentful towards services.

'Their needs weren't being met. They didn't investigate or start looking...to what might be going on with [son] in his mind...honestly they didn't care' (Mary, 105-110)

Parents appeared to feel particularly aggrieved by schools. They felt some teachers had little or no understanding of their child's needs and attributed their

difficulties to misbehaviour. This seemed to exacerbate parents feeling guilt and shame about their parenting abilities.

'Teacher who said Mr and Mrs [X] I don't know what more to do...because I think he [son] is un-teachable...I have been teaching...for 30 years now and I have never ever come across somebody like your son. And to me that was insulting' (Mary, 90-99)

2.4.2.2 'Just a parent'

Many of the parents in this study described feeling professionals did not listen or dismissed their concerns. This appeared to make parents feel insignificant and marginalised by professionals. Parents appeared to describe feeling that they were seen as 'just a parent', rather than the expert on their own child. This further added to the parent's inability to make sense of and understand their child.

'I said to be quite honest I have never seen an IQ test so badly done. And I was more or less told what do I know I was only a parent' (Beth, 25-28).

Rose discussed her attempts to get a diagnosis and support for her son was perceived by professionals as meeting her own rather her child's needs.

'I went to see my GP...I think he's got Asperger Syndrome ...response I got was it won't make him integrate any better the diagnosis is for parents. Erm which sounds horrid' (535-538)

Some of the parents appeared to experience services as inconsiderate of their child's needs. For example, James discussed how services could have responded differently if they had listened to his concerns regarding his daughter. Overall parents seemed to feel their interactions with services significantly contributed to the frustration and difficulties when raising their child.

'It's irritating in that when you lived with this child....you know what's going to happen. You know the triggers...when dealing with professionals and they tell you no it's going to be done this way ... you get the phone call they've pressed the button. She's gone off they've gone off...think does anybody listen' (James, 128-137)

The parents did have some positive interaction with services, as when their concerns appeared acknowledged and validated they seemed to feel grateful and listened to.

'It was just awesome at last there was someone [health professional] who understood' (Mary, 190-192)

2.4.3 Super-ordinate theme 3: 'Fear of the future'

Many of the parents in this study described feeling that their offspring's future was surrounded with uncertainty, especially when they could no longer support and care for them. The parents described their ideal service, which would enable their offspring to live a fulfilling and independent life.

2.4.3.1 The uncertain future

Parents appeared to worry about how service provisions would cater for their child's needs when they could no longer care for them and therefore appeared to feel uncertain about their offspring's future.

'With all Asperger mothers what happens if I drop dead tomorrow. Nobody's gonna look after their interests at the moment I just feel if they got somewhere to go...they got somebody. That's not a huge amount to ask' (Rose, 630-633)

Rose commented the AS diagnosis did not equate to receiving appropriate support and Laura felt the diagnosis alone was not enough to prepare her son for a future without her support. This further added to the uncertainty of their offspring's future.

'We have got this something great but there were no services...I phoned social services and no we can't do anything he is too able' (Rose, 564-568)

'From my point of view I'm still uncertain at what we should be making him do' (Laura, 404-405)

2.4.3.2 What we need for our children to *live* rather than *exist*.

The majority of the parents in this study appeared to view their offspring as a vulnerable adult because their difficulties were hidden from others. The parents described their ideal service for adults with AS, which would be a practical supportive service to enable them to live independently. Parents described their adult offspring needing support with the practical elements of independent living

and advocacy when needed. Laura felt services should acknowledge the vulnerability of adults with AS by comparing adult AS services to services for the elderly. Additionally parents described their adult offspring needing a support worker that could regularly 'check in' on them.

'Small complex of flats...learn how to pay bills or the things like that that independent living entail...like a warden someone who would call in and make sure everything was alright...A bit like the elderly people have' (Laura, 411-418)

Only three of the parents explicitly described needing services for parents who care for an adult with AS. This suggests parents may prioritise securing adequate future provisions for their child rather than concentrating on their own wellbeing.

'Need somewhere where parents can go and discuss the issues... being able to understand that you are not the only one out there' (James, 413-421)

Some of the parents also spoke about the importance of educating different professional groups, to promote an awareness of AS.

'First person you are going to go to is your GP...if doctors know or could point people, families in the direction of where to go' (Mary, 325-329)

Laura was the only parent to describe her son needing a friend to potentially live a fulfilling life.

'We only want him to have one friend that would change his life but it's been so difficult to find this person' (300-302)

2.5 Discussion

To date no study has explored parents' experiences of caring for their child who was diagnosed with AS in adulthood and only one study has explored parent's experiences of caring for an adult offspring with AS (Griffith et al., 2012). Research has been done on parents caring for an adult offspring with autism and developmental disabilities (Dillenburger and McKerr, 2009; Hines, Balandin & Togher, 2014). However, even though ASDs share the same core impairments in communication, social interaction and repetitive patterns of interests, individuals with AS can have a different presentation as they have an IQ level within the normal range and higher verbal abilities (Gray, 2003; Wing, 1991). This can make it difficult to extrapolate findings from studies on autism and developmental disabilities to AS.

Each super-ordinate theme in relation to the literature will now be discussed, followed by the methodological constraints, future research directions and the clinical implications.

2.5.1 'Parenting the unknown'

All parents in this study described raising their child was stressful and frustrating. The parents reported an overwhelming sense that they were parenting the unknown, as they were unable to make sense of their child's behaviour. These

experiences were congruent with the literature which also showed parents of children with AS experience high stress levels and sense that their child does not 'fit in' (Portway & Johnson, 2003).

The difficulties understanding their child's behaviour appeared to affect the parents in this study in a number of ways. The parents felt their parenting abilities were being judged by others (especially by school staff), which led to them feeling isolated. The most pervasive effect seemed to be the high levels of self blame. The parents described potentially not doing enough to pursue an earlier diagnosis and felt their lack of knowledge regarding their child's behaviour coupled with their parenting may have contributed to their child's difficulties. Interestingly, Wasserman, Weisman de Mamani and Mundy (2010) found parents caring for their adult offspring with autism made less blameworthy attributions of their behaviour than parents with an adult offspring with schizophrenia. This appeared to be due to the early recognition of autism in relation to schizophrenia, which allowed parents to understand from an earlier age that their child's behaviour was out of their control. The parents in the current study described their child's behaviour as 'awkward' or 'stubborn', therefore critically viewing their child's behaviour. This may suggest that parents of children diagnosed later in life may experience higher levels of self blame, as they potentially lack a framework to understand their child's behaviour. Chell (2006) also found parents described the time without their child being diagnosed with AS, as isolating, blaming and felt unable to adjust to their child's behaviour.

This study therefore highlights the importance and need to recognise and diagnose AS earlier. A diagnosis can provide parents with a framework to make sense of their child's behaviour (Malloy & Vasil, 2008). Lasser and Corley (2008) reported the AS diagnosis allows parents to construct a sense of normalcy whereby they can adjust their parenting style and the environment to their child's needs. An AS diagnosis has also been reported to provide the parents with: relief from potentially feeling guilt and blame of their child's difficulties, acceptance of their limitations and a positive embracement of their differences (Clarke & Amerom, 2008; Malloy & Vasil, 2008; Tantum, 1991). This study also found parents appeared to feel relieved and less guilty when their offspring received an AS diagnosis.

The parents in this study appeared to cope with the stresses of raising their child using emotion focused (religion, significant others) rather problem focused coping⁶. However, many of the parents in this study did not appear to know the cause of their child's difficulties and therefore were unaware of how to change their situation. Furthermore, the parents appeared to perceive professionals as dismissive of their concerns; further relying on emotion focused coping. Gray (2006) found parents with a child diagnosed with autism coped using problem

⁶ Lazarus (1993) proposed that there are two functional components to coping, which are problem focused and emotion focused. Problem focused coping involves acting on the environment or the self to elicit change in the stressor. Emotion focused coping involves changing the way the individual attends to the stressor. In this instance the stressor may be the child's difficulties.

focused strategies (accessing specialised autism treatment services and personal counselling services). However, as the child became an adult, parents tended to cope using emotion focused strategies (religion and contact with others). Gray (2006) reported this may have been because parents had access to fewer services when their child became an adult or were more attuned and accustomed to their child's difficulties. This suggests it may be beneficial to promote emotion focused coping strategies to parents whose child receives a late diagnosis, as they may have access to fewer services and be more familiar and reliant on emotion focused coping.

This study found all the mothers recognised their child's behaviour as different and potentially a cause for concern in comparison to the fathers. O'Halloran, Sweeney and Doody (2013) also found fathers of children with AS were less likely to recognise their child's behaviour as different and concerning, and this was usually brought to their attention by their spouses. Gray (1997, 2003) investigated the role of mothers and fathers of children with high functioning autism or AS and found they functioned within traditional gender roles. The mothers appeared to be more responsible for child raising and as a result more self blaming of their child's difficulties. The fathers seemed to spend less time with their child because of their work commitments. This may therefore explain why mothers are more attuned to their child's behaviour and more invested in recognising that their child behaves differently to others. Little (2002) also found mothers experience greater stress levels than fathers of children with ASD.

In this study many of the parents seemed to grapple with the notion of their child being 'normal', as the parents appeared to minimise their child's difficulties but yet recognised that they behaved differently from other children. Whilst this appears contradictory, parents may have minimised their child's difficulties because they perceived professionals and themselves as unable to make sense of their child's difficulties. Siegel (1997) reported an AS diagnosis can invalidate parents' fantasy of having the 'hoped for' child. Parents therefore appear to re-adjust to having a child with a developmental disability (Mount & Dillon, 2014). Furthermore, Siegel (1997) reported children with autism physically appear normal, which can challenge parents' knowledge that something is wrong with their child. Many of the parents in this study described feeling sad when their offspring received an AS diagnosis. Some of the parents appeared to grieve the death of their 'hoped for' healthy child and felt their child would no longer be able to live a 'normal' life. Other research has also found a diagnosis of AS can evoke a grief reaction in parents (Chell, 2006; Moyes, 2003). This grief reaction should therefore not be underestimated in parents whose child receives a late diagnosis.

2.5.2 'Services fumbling in the dark'

All the parents in this study to varying extents described their interactions with services negatively, as they appeared to feel their concerns were dismissed and

therefore invalidated. Chell (2006) and Schall (2000) found parents of children with autism or AS perceived services as disregarding of their opinion and blaming.

Parents in this study described meeting different professionals from the health and education sector and received little or no resolution of their child's difficulties. Parents seemed to attribute this to professionals lack of knowledge, awareness and recognition of AS. Many of the parents in this study appeared to find this frustrating and in hindsight felt their child had missed opportunities of care and therefore seemed aggrieved with services. Carlson, McGeorge and Halvorson, (2007) investigated whether clinicians could correctly diagnose AS in a hypothetical scenario. They found AS was only correctly diagnosed 20.5% of the time. It was felt this was due to the lack of awareness of AS amongst the clinicians (Carlson et al., 2007). Goin-Kochel et al. (2006) found parents whose children were diagnosed with ASD at a later age, had more interactions with services and were most dissatisfied with the diagnostic process. This highlights the importance of promoting an awareness of AS, as found in other research (Chell, 2006).

Interestingly, only two parents in this study described their child receiving other psychiatric disorders and wondered whether this contributed to their child receiving a late diagnosis of AS. It was envisaged that more of the parents in this study would have experienced their child receiving other psychiatric disorders, as AS is highly co-morbid with other psychiatric disorders (Tantum, 1991). Stoddart (1999) also found in three separate case studies a contributing factor to the child

receiving a diagnosis of AS later was because their difficulties were previously alternatively explained. However, the current study was not intended to reflect all parents' experiences, as IPA concerns itself with the in-depth understanding of an individual's experience of a particular phenomenon (Smith et al., 2009).

2.5.3 'Fear of the future'

The main concern for the parents appeared to be the anxiety and uncertainty of their child's future when they could no longer care for them. The parents described their offspring needing lifelong potentially low level support, which acknowledged their vulnerabilities. The parents in this study appeared to describe their adult offspring needing a substitute parent. Griffith et al. (2012) also found parents who cared for their adult offspring with AS, were highly concerned of their child's future and felt services needed a better understanding of AS to provide adequate care provisions. These parents also felt their adult offspring would benefit from a 'mentor' figure. Other research exploring parents experiences of caring for an adult with ASD or developmental disabilities also found parents worry how services will adequately care for their offspring in the future (Hines, Balandin & Togher, 2014; Minnes & Woodford, 2004). Even with major legislation breakthroughs regarding services for adults with autism (Autism Act, 2009) parents still appear to experience anxiety about future service provision for their adult offspring.

Interestingly, the parents in this study were asked how services could 'support their needs' and only two parents commented on what could personally help them. This potentially indicates services that effectively support adults with AS may vicariously also support the needs of parents.

2.5.4 Methodological constraints

The current study had a small purposeful sample in line with IPA. However it is important to note, all participants were recruited from a voluntary support organisation. This may have resulted in a selection bias as there may be differences in parental experiences of those who do and do not access support organisations. Furthermore the sample mainly consisted of mothers and therefore may not accurately represent the experiences of fathers.

One of the participants had her offspring present during the interview. It was felt that this may have acted as a limitation as the parent may have felt restricted to discuss the difficulties of raising her child. However, it seemed the presence of her offspring appeared to be cathartic, as it provided a platform for the parent to tell her story and talk about feeling proud of her son, despite his difficulties.

2.5.5 Future research

Future research may benefit from targeting specific participant groups, such as fathers or single parent's. This would help investigate gender and family construction differences, as Gray (1997) reported traditional gender roles can influence how parents raise their child.

Some of the parents in this study commented that the difficulties of raising their child with AS negatively impacted on the siblings. Research has shown siblings can feel they are second place because of the demands placed on the parents by the child with AS (Dellve, Cernerud, Lillemor & Hallberg, 2000) and raising a child with autism may contribute to psychiatric difficulties in the siblings (Lainhart, 1999). Further qualitative exploration of siblings' experiences is recommended.

In light of the diagnostic changes of ASD in the DSM-5, qualitative exploration of individuals with AS and their parents views may further enhance our understanding of how ASD is viewed. This could potentially support individuals through this major diagnostic change.

2.5.6 Clinical implications

A number of themes have been highlighted in this study, the most pertinent of which was the lack of recognition, awareness and education of AS amongst

different professional groups. Parents in this study described this having a significant effect on their ability to parent and understand their child's needs, which negatively impacted on their well being. This study therefore supports other research highlighting the need to further educate different professional groups (health, education, employment) on the subtleties of AS, so that it can be recognised and detected earlier (Aylott, 2010; Chell, 2006; Griffith et al., 2012; Mount & Dhillon, 2014). However, this is currently complicated by diagnostic discrepancies and by the removal of AS from the DSM-5. Nevertheless this could potentially reduce discrimination and promote the positive acceptance of individuals with autism, which has also been advocated by the Department of Health (DoH) in their, 'Think Autism: 'fulfilling and rewarding lives': strategy for adults with autism in England' publication (DoH, 2014).

The current study highlighted parents felt there were a lack of services available to adults with autism, as some commented that the diagnosis led to inappropriate or no services at all. Following the implementation of the Autism Act in 2009, the DoH, NICE and Social Care Institute of Excellence (SCIE) have all produced publications around strategies to improve care for adults with autism (DoH, 2010, 2014; NICE, 2012, SCIE, 2011). These publications describe services that should aim to support adults with autism to live independently, whilst recognising when they may benefit from an advocate. They highlight the need for post diagnostic support, which should be tailored to the needs of the individual. They further describe the importance of discussing future planning with family members. The

successful implementation of these guidelines would recognise the unique experiences of parents who care for an adult offspring with AS. This may also help foster positive relationships between services and families and encourage parents to feel supported by service organisations. This may reduce stress levels and mental health difficulties in parents who care for their adult offspring with AS.

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Chapter 3

My experience of qualitative methodology and the impact of diagnostic labels.

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3.1 Abstract

This chapter consists of two sections. Firstly, the researcher provides a reflective account of their experience of conducting qualitative research, especially focusing on the interview process and the differences between conducting an interview as a researcher and clinician. Secondly, the researcher reflects on their view and use of diagnostic labels, specifically Asperger Syndrome and its removal from the Diagnostic and Statistical Manual for mental disorders 5th Edition (DSM-5).

Key words: Qualitative research, Diagnosis, Asperger Syndrome and DSM-5.

3.2 Introduction

This paper is made up of two sections. Firstly I will be reflecting on my experience as a qualitative researcher. I will then go on to discuss and reflect on my thoughts of diagnostic labels; are they a friend or a foe?

3.3 Qualitative research

I was keen to use a qualitative methodological approach, as I wanted to represent as fully as possible the stories and experiences of a particular group of individuals. Alongside this I was aware of my avoidance of conducting quantitative research. I felt this was heavily influenced by my previous minimal research experience and more extensive clinical experience. My clinical experience has shown me the quality of information that can be obtained from therapeutically conversing with clients and conducting psychometric assessments. I felt that I had applied this knowledge to how qualitative and quantitative research methodologies may generate conclusions obtained from different data collection sources. I also found myself drawn to conversing and interacting with people rather than administering an assessment measure. However, I felt that a part of me was overwhelmed with the thought of conducting quantitative research and completing complex statistical analysis. I therefore felt I would be most suited and comfortable using a qualitative methodology. This awareness has now sparked an interest in me to explore and potentially conduct research, using quantitative methods.

The methodology I therefore chose to use was: Interpretative Phenomenological Analysis (IPA). IPA aims to explore in a detailed manner an individual's personal account of a particular object or event (Smith, Flower & Larkin, 2009). I began the interview process, believing it would be the least stressful part of the research, as I enjoy interacting with people and I was curious about what the parents' experiences may hold. However, this was far from my experience. The interview process has made me reflect on three main issues: the interview process itself, my desire for the perfect interview and the different emotions I experienced.

3.3.1 The interview process

I quickly realised my naivety about the interviewing process and realised how skilful one had to be to effectively interview others using IPA interviewing techniques (Smith, 2003). My experiences as a clinician helped me to create a comfortable setting for the individual, gauge how they might be feeling and how best to reassure them regarding the interview. However, I found conducting a research interview was different to clinical interviews, which was further exaggerated by my minimal research experience. During the interview process one of the parents that I interviewed continuously digressed from the research topic and discussed his own healthcare issues, which seemed highly pertinent to him at the time. Upon reflection I found it highly uncomfortable to ask the parent to focus on the research topic as I felt that I was dismissing something that was

important to him. I also wondered whether this may have been a defence to not discuss his parenting experience as it may have been too difficult to verbalise or share with another. This made me think about the differences between the role of a clinician and researcher. In a clinical setting a digression from the topic by the individual would have been a probing discussion point, whereas as a researcher I was mindful of bringing the parents focus back to the research topic. I found reflecting after each interview extremely helpful, as it helped adapt my interview technique and increase my confidence, which allowed me to conduct more fluid interviews and embrace the differences between being a researcher and clinician.

3.3.2 The perfect interview

Before each interview I *naturally* desired to have the perfect interview, which I envisaged to be a rich, in depth, highly eventful exploration of the parent's experiences. I hoped that all the parents had a colourful, dramatic, difficult or interesting journey in obtaining their child's diagnosis. I felt particularly deflated after one interview, as I felt it was not rich or in depth enough. At the time of the interview, I felt I was wasting my time and did not think the interview would add to the research. On reflection I realised that I was hoping the parents would have extra-ordinary and difficult experiences. I was surprised by my somewhat sadistic thoughts of what I wanted parents to have experienced. I found this was driven by my need and expectations to have the 'perfect interview' and for all issues that

had been reported in previous research regarding parents experiences of having a child diagnosed with Asperger Syndrome (AS) to be present in this study.

I kept a reflective diary throughout the interview process. This allowed me to reflect on my fantasies of what I imagined conducting research would be like and the realities of actually conducting research on peoples experiences. Following these experiences I was able to proceed with the interviews with more ease, as I was less concerned about the 'perfect interview'. I therefore fully embraced the parents' personal construct of their experiences and perceptions. Furthermore this helped me to understand the thought processes that I was bringing to the interview and made me more aware of the role that I played as the researcher. The awareness of my own thought processes was further enhanced by the bracketing interview⁷, which allowed me to mindfully continue the interviews and 'freely' listen to the parents.

3.3.3 Emotional interviews

I began the research knowing that the interviews could be highly emotive for the parents and put precautions in place, such as time at the end of the interview to fully debrief the parents and provide them with details of my clinical supervisor, should they wish to discuss any issues that may have arisen during the interview.

⁷ A bracketing interview allows the researcher to reflexively put aside and bracket their preconceptions and personal feelings that could subjectively bias the interpretation of the results and interview process (Ahern, 1999).

However I did not fully consider the extent the interviews may emotionally affect me. I found myself wanting to jump into a clinician role and normalise the parents' experiences; especially when they described their parenting abilities in a highly critical way and were very judgemental of themselves.

For example participants said:

'I know this is not a very nice thing to hear but...you are going to think aren't I horrible at times I shook him because what do I do' (Mary, 166-168)

'There were tears really thinking back...I just didn't know what else to do. I felt a failure and a lot of guilt' (Rose, 387-390)

At times, I felt it was my responsibility to help parents resolve issues that they still seemed to be struggling with. I wanted to let parents know that they may benefit from seeing a health professional. I struggled to decide whether it was appropriate to interrupt parents and normalise their feelings, as this risked disrupting the parents' flow of telling their story. I felt ethically challenged at such times as I felt I was deciding to maximise the individual being able to tell their story, which is an important aspect of IPA (Smith et al., 2009) but at the expense of the parents' feelings. The debriefing process allowed me some element of resolving this ethical dilemma and equalising my own uncomfortable feelings. The debriefing process gave the parents a platform to discuss how they felt following the interview and to reflect on the story that they had shared. Furthermore, many

of the parents were telling their story for the first time, hence unable to predict the feelings that may have surfaced. These issues highlighted that conducting research of a sensitive nature requires appropriate safety precautions. For example a named individual the participants can contact should they feel the need to do so.

Conducting these interviews, led me to reflect on the time I spent working in teams where children or adults were diagnosed with AS. In the adult team, adults were assessed for AS and if they met the diagnostic criteria were offered the diagnosis AS. In the child team, children were assessed for Autism Spectrum Disorders (ASD) and offered the diagnoses ASD or AS. Both teams were multi-disciplinary and completed a range of psychological assessments with the individual and interviewed the parents to gain a detailed childhood history of the individual. In both teams the majority of the work was completed with the individual under assessment. A small amount of time was spent with the parents, mainly to obtain a childhood developmental history for the diagnostic assessment.

In the child team the parents were consulted when delivering the diagnosis. This was the only opportunity for parents to discuss their child's diagnosis. However, this meeting was predominately to describe the next steps in the child's care and did not address the impact of the diagnosis on the parent's. This may have been because the team's remit was centred on assessment and diagnosis and not follow up support. The team were only able to signpost parents to charity

organisations and school support services. They only saw parents again if it was deemed clinically irresponsible not to. In the adult team parents were not consulted when delivering the diagnosis, as the team solely worked with the adult. I found this way of working uncomfortable and felt the teams were neglecting the feelings and experiences of the parents. I distinctly remember feeling a disparity between wanting to help the family holistically and only being able to offer what the service could realistically provide. At the time I was working as a Trainee Clinical Psychologist and felt unable to influence the team's processes around post diagnostic support. Many of the team members also felt that they were offering a very limited post diagnosis service to family members, but were aware of the services remit and the pressures placed on the team. The child team also seemed to be in a constant state of having to prove its existence and effectiveness as a specialist diagnostic team. This exposed me to the many dilemmas that are present in clinical services and the importance of conducting research in under researched areas, in order to be able to tackle service provision issues.

Throughout the interviews, many parents seemed to describe receiving little or inappropriate support from the National Health Service (NHS). I felt saddened by this and I personally felt disappointed that I was working for an organisation (NHS) that seemed to have let the parents down. This showed me the importance and benefits of working systemically in specialist ASD diagnostic teams as an ASD diagnosis affects not just the individual but the family too (Portway & Johnson,

2003). This research made me consider how I would like to shape and influence services once qualified as a Clinical Psychologist. I believe services that are holistic in their approach would better serve the individual and wider family, as educating and supporting the network of people (family members and professionals) around the individual will potentially benefit the individual. This network of people around the individual would therefore have a greater understanding of the individual and may feel better equipped to manage difficulties the individual may encounter. Interestingly, many of the parents that were interviewed described their child with AS as vulnerable. The parents further felt their child would benefit from a support worker who could periodically 'check' on them when they were no longer able to care for them. This further highlights the need for people with AS to have a network of people around them that have a good understanding of AS.

On a personal level, the strength the parents whom were interviewed demonstrated in their personal journeys, made me reflect on my personal experiences as a mother. I was struck by the unconditional support, strength and resilience the parents provided throughout their child's life. Furthermore, the parents seemed to view everything they did and the emotions they felt, as just part and parcel of being a parent and did not see their behaviour as extraordinary. This has allowed me to put my own dilemmas into perspective and think about my own protective factors. This also filled me with hope that I too, as a mother could potentially display such strength when faced with upheaval.

3.4 Diagnosis – friend or a foe?

My empirical paper revolved around the impact of an AS diagnosis. This has made me reflect on how I viewed diagnostic labels when working as a clinician in mental health and specialist diagnostic teams and how my understanding of them has changed having completed this research.

As a Trainee Clinical Psychologist I have been heavily influenced by the importance of formulating and using formulations in clinical practice rather than the diagnosis. A formulation as defined by the Division of Clinical Psychology (DCP) is the:

‘Summation and integration of the knowledge that is acquired by this assessment process...The formulation will draw on psychological theory and research to provide a framework for describing a client’s problem or needs, how it developed and is being maintained.’ (*DCP, 2010, p.5*).

The formulation is therefore used to help the individual understand their dilemmas and to guide the clinicians choice of intervention (Johnstone & Dallos, 2006).

Working as a Trainee Clinical Psychologist in mental health teams, I have always focused on an individual’s formulation. I only considered their diagnosis for

information purposes rather than to understand the individual and their difficulties. In line with Wheeler (2011) a formulation allows you to holistically look at the individual and consider many aspects of their dilemmas and issues, whereas a diagnosis can lead to a reductionist symptomatology view of the individual. I also felt that individuals had to fit a diagnostic label whereas a formulation was unique and 'fit' the individual. Working in a mental health setting, I found the diagnosis told me very little about the person and most of my therapeutic work revolved around individual's present difficulties rather than their diagnosis. I felt that for some individuals the diagnosis acted as a hindrance, as the patient would begin to negatively associate themselves with the diagnosis or see themselves as 'defective'. I was therefore somewhat dismissive of diagnostic labels and viewed them as unhelpful and negative. On reflection this could have been due to my lack of understanding of diagnostic categories and because the focus of my training was on formulation. This research and my experiences of working in specialist diagnostic teams have made me reflect on how individuals may perceive their diagnosis. Interestingly, the DCP (2013) stated diagnostic classification systems are limited in their ability to determine intervention. They can also de-contextualise the individual's difficulties, by neglecting links between people's experiences and their social and cultural environment. The DCP (2013) argued a multi factorial approach is needed that contextualises the individual's difficulties and behaviours.

From my own experiences of working clinically with children and adults diagnosed with AS, I was able to discuss with them, their experiences of having AS. I was struck by the distinctively different ways the individuals used their diagnosis. I found some of the individuals externalised their difficulties and attributed them to their diagnosis. The diagnosis therefore appeared to be negatively associated with their perceived difficulties and these individuals seemed to resent their diagnosis. Others however, seemed to embrace the diagnosis and felt a sense of relief, as they previously viewed themselves as 'strange' or 'weird' and the diagnosis allowed them to make some sense of their difficulties. They also appeared to use their diagnosis to re-frame how they viewed themselves. My experiences of how individuals have viewed their diagnosis are in line with the research in this area (Malloy & Vasil, 2004; Punshon, Skirrow & Murphy, 2009) This experience has given me the opportunity to reflect on the different ways individuals use their diagnosis and made me consider the importance of discussing diagnostic labels with individuals in clinical settings, as the diagnosis may be seen as a 'friend or a foe'.

This experience was further enhanced when I spent some time with individuals who accessed a voluntary organisation called Aspie, which was a group for people who had or knew someone with AS. Here I met a number of individuals with AS. I was struck by the way the group members referred to themselves as 'Aspies', which meant someone who has affiliated themselves with the AS diagnosis. The term Aspie was used with pride and the group appeared to resemble a small

community where its members felt accepted and free to express themselves as having AS. Individuals from the group commented that the term Aspie allowed them to help explain their strengths and weaknesses to 'neurotypicals' (someone who they termed not to have an AS brain). I did not expect the diagnostic label AS to be so well received by those who had it. This made me consider how such individuals may feel with the removal of AS from the Diagnostic and Statistical Manual for mental disorders fifth edition (DSM-5).

I never imagined that changes in a diagnostic manual would resonate with me. The DSM-5 has made significant changes to the category Autism Spectrum Disorders. Previously individuals could receive one of four diagnoses under the Autism Spectrum category, one of which was AS. In the fifth edition a single umbrella term: Autism Spectrum Disorder will be used to capture the range of Autism Spectrum disorders, without compromising the sensitivity of the criteria (American Psychiatric Association, 2013).

I felt a sense of unease of the removal of AS from the diagnostic manual. It made me consider the effect this change would have on those with an AS diagnosis and how it would affect the future of specialist AS services. Researchers have reported that it may be premature to amalgamate AS with autism, as there may be significant differences between them that need to be thoroughly researched (Kaland, 2011). Furthermore, the exclusion of AS may have negative clinical implications, as it may cause anxiety and stress in individuals already diagnosed

with AS and make them seek out health professionals to clarify their diagnosis (Kaland, 2011). However Cashin (2006) suggested the term autism and AS point to the same entity. This can therefore create cognitive inefficiency, confusion, distress amongst individuals and their families and potentially make the diagnostic process unreliable. My research has shown me that diagnoses are more than just a collection of symptoms or characteristic traits and changes in a diagnostic category could affect a range of different people and systems.

This research further made me question the idea of categorising AS as a diagnostic mental health condition, as many of the 'Aspies' I met appeared to view themselves as different to 'normal' people and not inferior, deficient or having a disorder. Some researchers have reported that AS should be considered as a social difference and not seen as a diagnostic disorder. Wheeler (2011) argues the characteristics of AS should be viewed as a socially imposed disability, which potentially means individuals with AS may have difficulty accessing some aspects of society, such as employment and higher education. Allred (2009) states AS should be seen as a human difference rather pathologised as an illness or mental disorder. However, Allred (2009) also stated that this view of AS could negatively impact on the care, accommodation and social benefits that individuals with AS may receive. This has further made me consider the impact that society's values and ideas can have on a particular group of people. This is important to be mindful of when working with individuals that could potentially be negatively categorised by society.

Having completed this research, I now have a vastly different appreciation of diagnostic labels. I have been able to vicariously experience, how individuals accept or reject their diagnosis and how they integrate their diagnosis into their world and their identity. It has allowed me to see the impact a diagnosis can have on family members, individuals, clinicians, researchers, service provisions and wider society. I feel this research has made me engage with the debate around the medicalised diagnostic categorisation of human behaviour (DCP, 2013). I currently feel unsure as to my position within this debate, as I have been able to see the positive and negative effects a diagnosis can have on an individual. I hope to have an active involvement within this debate during my future clinical career, as I now no longer see a diagnosis as a collection of symptoms or characteristics. This research has also made me more mindful of how I would use diagnostic labels in my future clinical career.

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Appendix 1: Author guidelines for submission to Social Science and Medicine Journal



Guide for Authors

- *Social Science & Medicine* provides an international and interdisciplinary forum for the dissemination of social science research on health. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health and healthcare from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and the organization of healthcare. We encourage material which is of general interest to an international readership.
- *Journal Policies*
The journal publishes the following types of contribution:
 - 1) Peer-reviewed original research articles and critical analytical reviews in any area of social science research relevant to health and healthcare. These papers may be up to 8000 words including abstract, tables, and references as well as the main text. Papers below this limit are preferred.
 - 2) Peer-reviewed short reports of findings on topical issues or published articles of between 2000 and 4000 words.
 - 3) Submitted or invited commentaries and responses debating, and published alongside, selected articles.
 - 4) Special Issues bringing together collections of papers on a particular theme, and usually [guest edited](#).



Preparation

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- **NEW SUBMISSIONS**

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.

As part of the Your Paper Your Way service, you may choose to submit your manuscript as a single file to be used in the refereeing process. This can be a PDF file or a Word document, in any format or lay-out that can be used by referees to evaluate your manuscript. It should contain high enough quality figures for refereeing. If you prefer to do so, you may still provide all or some of the source files at the initial submission. Please note that individual figure files larger than 10 MB must be uploaded separately.

- **References**

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

- **Formatting requirements**

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

Divide the article into clearly defined sections.

- ***Formatting Requirements***

The journal operates a double blind peer review policy. For guidelines on how to prepare your paper to meet these criteria please see the [attached guidelines](#). There are no other strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

Divide the article into clearly defined sections.

- **REVISED SUBMISSIONS**

- ***Use of word processing software***

Regardless of the file format of the original submission, at revision you must provide us with an editable file of the entire article. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: <http://www.elsevier.com/guidepublication>). See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

- **Essential cover page information**

The Cover Page should **only** include the following information:

- **Title.** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible and make clear the article's aim and health relevance.
- **Author names and affiliations in the correct order.** Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
- **Corresponding author.** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address. Contact details must be kept up to date by the corresponding author.**
- **Present/permanent address.** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.
- **Text**
In the main body of the submitted manuscript this order should be followed: abstract, main text, references, appendix, figure captions, tables and figures. Author details, keywords and acknowledgements are entered separately during the online submission process, as is the abstract, though this is to be included in the manuscript as well. During submission authors are asked to provide a word count; this is to include ALL text, including that in tables, figures, references etc.

- **Title**

Please consider the title very carefully, as these are often used in information-retrieval systems. Please use a concise and informative title (avoiding abbreviations where possible). Make sure that the health or healthcare focus is clear.

- **Abstract**

An abstract of up to 300 words must be included in the submitted manuscript. An abstract is often presented separately from the article, so it must be able to stand alone. It should state briefly and clearly the purpose and setting of the research, the principal findings and major conclusions, and the paper's contribution to knowledge. For empirical papers the country/countries/locations of the study should be clearly stated, as should the methods and nature of the sample, the dates, and a summary of the findings/conclusion. Please note that excessive statistical details should be avoided, abbreviations/acronyms used only if essential or firmly established, and that the abstract should not be structured into subsections. Any references cited in the abstract must be given in full at the end of the abstract.

- **Research highlights**

Research highlights are a short collection of 3 to 5 bullet points that convey an article's **unique contribution to knowledge** and are placed online with the final article. We allow 85 characters per bullet point including spaces. They should be supplied as a separate file in the online submission system (further instructions will be provided there). You should pay very close attention to the formulation of the Research Highlights for your article. Make sure that they are **clear, concise and capture the reader's attention**. If your research highlights do not meet these criteria we may need to return your article to you leading to a delay in the review process.

- **Keywords**

Up to 8 keywords are entered separately into the online editorial system during submission, and should accurately reflect the content of the article. Again abbreviations/acronyms should be used only if essential or firmly established. For empirical papers the country/countries/locations of the research should be included. The keywords will be used for indexing purposes.

- **Methods**

Authors of empirical papers are expected to provide full details of the research methods used, including study location(s), sampling procedures, the date(s) when data were collected, research instruments, and techniques of data analysis. Specific guidance on the reporting of qualitative studies are provided [here](#).

- Systematic reviews and meta-analyses must be reported according to [PRISMA](#) guidelines.

- **Footnotes**

There should be no footnotes or endnotes in the manuscript.

- **Figure captions**

Ensure that each illustration has a caption. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

- **Tables**

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

- **References**

- **Citation in text**

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full at the end of the abstract. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal (see below) and should include a substitution of the publication date with either “Unpublished results” or “Personal communication” Citation of a reference as “in press” implies that the item has been accepted for publication.

- **Web references**

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

- **References in special issue articles, commentaries and responses to commentaries**

Please ensure that the words ‘this issue’ are added to any references in the reference list (and any citations in the text) to other articles which are referred to in the same issue.

- **Reference formatting**

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable,

author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct. If you do wish to format the references yourself they should be arranged according to the following examples:

- **Reference style**

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK.

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Examples:

Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51–59.

Reference to a book:

Strunk, W., Jr., & White, E. B. (2000). *The elements of style*. (4th ed.). New York: Longman, (Chapter 4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.

- **Supplementary data**

Elsevier accepts electronic supplementary material to support and enhance your research. Supplementary files offer the author additional possibilities to publish supporting applications, accompanying videos describing the research, more detailed tables, background datasets, sound clips and more. Supplementary files supplied will be published online alongside the electronic version of your article in Elsevier Web products, including ScienceDirect: <http://www.sciencedirect.com>. In order to ensure that your submitted material is directly usable, please provide the data in one of our recommended file formats. Authors should submit the material in electronic format together with the article and supply a concise and descriptive caption for each file. For more detailed instructions please visit our artwork instruction pages at <http://www.elsevier.com/artworkinstructions>.

Appendix 2: Author guidelines for submission to Research in Autism Spectrum Disorders Journal



Preparation

- Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: <http://www.elsevier.com/guidepublication>). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

- Article structure
- *Subdivision – numbered sections*

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

- **Introduction**
State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.
- **Material and methods**
Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.
- **Theory/calculation**
A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.
- **Results**
Results should be clear and concise.
- **Discussion**
This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.
- **Conclusions**
The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.
- **Appendices**
If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.
- **Essential title page information**
 - Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
 - Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
 - Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that the e-mail address is

given and that contact details are kept up to date by the corresponding author.

- Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

- **Abstract**

An abstract should be submitted that does not exceed 200 words in length. The abstract should be brief, concise, and complete in itself without reference to the body of the paper. Include purpose, methodology, results, and conclusions where applicable.

- **Highlights**

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See <http://www.elsevier.com/highlights> for examples.

- **Keywords**

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

- **Abbreviations**

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

- **Acknowledgements**

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

- **Footnotes**

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

- **Figure captions**

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (not on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

- **Tables**

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

- **References**

- ***Citation in text***

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

- ***Web references***

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

- ***References in a special issue***

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

- **Reference style**

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK.

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Examples:

Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51–59.

Reference to a book:

Strunk, W., Jr., & White, E. B. (2000). *The elements of style*. (4th ed.). New York: Longman, (Chapter 4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.

- **Additional Information**

The word *retarded* should be used as an adjective rather than a noun; *retardate* should be avoided. Terms that are scientifically precise should be adhered to.

Therefore, *mentally retarded* will be preferred to *retarded* because it specifies the type of retardation, and *intellectually average* or *normal intelligence* will be preferred over *normal*. A similar format should be followed if other disabilities are involved. It is understood that all investigations have been approved by the human subjects review committee of the author's institution.

Appendix 3: Author guidelines to Reflective Practice: International and Multidisciplinary Perspectives Journal



This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Use these instructions if you are preparing a manuscript to submit to *Reflective Practice*. To explore our journals portfolio, visit <http://www.tandfonline.com/>, and for more author resources, visit our [Author Services](#) website.

Reflective Practice considers all manuscripts on the strict condition that

- the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.
- the manuscript has been submitted only to *Reflective Practice*; it is not under consideration or peer review or accepted for publication or in press or published elsewhere.
- the manuscript contains nothing that is abusive, defamatory, libellous, obscene, fraudulent, or illegal.

Please note that *Reflective Practice* uses [CrossCheck™](#) software to screen manuscripts for unoriginal material. By submitting your manuscript to *Reflective Practice* you are agreeing to any necessary originality checks your manuscript may have to undergo during the peer-review and production processes.

Any author who fails to adhere to the above conditions will be charged with costs which *Reflective Practice* incurs for their manuscript at the discretion of *Reflective Practice's* Editors and Taylor & Francis, and their manuscript will be rejected.

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4. General guidelines

- Manuscripts are accepted in English. British English spelling and punctuation are preferred. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Long quotations of 40 words or more should be indented with quotation marks. No Article types required
- A typical manuscript will not exceed 6000 words including tables, references, captions, footnotes and endnotes. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- [Abstracts](#) of words are required for all manuscripts submitted.
- Each manuscript should have 3 to 6 [keywords](#).
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#).
- Section headings should be concise.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Please supply a short biographical note for each author.
- Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate paragraph, as follows:
- *For single agency grants:* “This work was supported by the [Funding Agency] under Grant [number xxxx].”

- *For multiple agency grants:* “This work was supported by the [Funding Agency 1] under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx].”
- Authors must also incorporate a [Disclosure Statement](#) which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to [SI units](#). Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed [equations](#) or image files within their manuscript

5. Style guidelines

- [Description of the Journal’s article style.](#)
- [Description of the Journal’s reference style.](#)
- An [EndNote output style](#) is available for this journal.
- [LaTeX template.](#)
- [Word templates](#) are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk.

3. Figures

Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.

- Figures must be saved separate to text. Please do not embed figures in the manuscript file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).

- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

Manuscript submission

All submissions should be made online at the *Reflective Practice* [Scholar One Manuscripts](#) website. New users should first create an account. Once logged on to the site, submissions should be made via the Author Centre. Online user guides and access to a helpdesk are available on this website.

Manuscripts may be submitted in any standard editable format, including Word and EndNote. These files will be automatically converted into a PDF file for the review process. LaTeX files should be converted to PDF prior to submission because ScholarOne Manuscripts is not able to convert LaTeX files into PDFs directly. All LaTeX source files should be uploaded alongside the PDF.

Last updated 26/09/2014

Appendix 4: Quality Framework

Study	Yes (2)	Partially (1)	No (0)
Does the title reflect the content?			
Are the authors credible?			
Does the abstract summarise the key points?			
Is the rationale for undertaking the research clearly defined?			
Is the literature review up to data and comprehensive?			
Is the aim(s) of the research clearly stated?			
Are ethical issues identified and addressed?			
Quantitative research questions on methodology			
Is the study design identified and its rationale evident?			
Is there an experimental hypothesis clearly stated			
Are the key variable defined? (IV and DV)			
Is the population identified?			
Is the sample (and comparison group if applicable) adequately described and reflective of the population?			
Is the method of data collection valid and reliable?			
Is the method of data analysis valid and reliable?			
Is some estimate of variance reported?			
Has the study controlled for confounding variables?			
Qualitative research questions on methodology			
Are the philosophical background and study design identified and rationale for choice of design evident?			
Are the major concepts identified and defined?			
Is the context of the study outlined?			

Is the selection of participants described and sampling method identified?			
Is the data collection method clearly described and systematic?			
Is the data analysis clearly described and systematic?			
Use of verification procedures to establish credibility?			
Reflexivity account provided by the researcher			
Results and discussion quality checks for all papers			
Are the results presented in ways that are appropriate and clear?			
Is the discussion comprehensive?			
Is the conclusion comprehensive?			

Appendix 5: Quality rating scores for the studies included in the literature review.

Each quality criterion was scored 2 if answered yes, 1 if answered partially and 0 if answered no.

Quantitative studies	Qualitative studies
A = Alferi, Culver, Carver, Arena & Antoni, 1999 B = Culver, Arena, Antoni & Carver, 2002 C = Ebright & Lyon 2002 D= Gall, Charbonneau & Florack. 2011 E = Gall, Guirguis-Younger, Charbonneau & Florack. 2009 F = Herbert, Zdaniuk, Schulz & Scheier 2009 G = Jim, Richardson, Golden-Kreutz & Anderson. 2006 H = Pedersen, Christensen, Jensen & Zachariae 2013 I = Stanton, Danoff-Burg & Huggins, 2002 J = Thunè-Boyle, Stygall, Keshtgar, Davidson & Newman. 2013.	K = Feher and Maly 1999 L = Landmark, Strandmark & Wahl. 2001 M = Northouse 1989 N = Taleghani, Yekta & Nasrabadi,2005

Quality ratings for the quantitative studies

Study	A	B	C	D	E	F	G	H	I	J
Title reflect the content?	2	2	2	2	2	2	2	2	2	2
Are the authors credible?	2	2	2	2	2	2	2	2	2	2
abstract include key points?	2	2	2	2	2	2	2	2	2	2
Rationale of research?	2	2	1	2	2	2	2	2	2	2
Is the literature up to date?	2	2	2	2	2	2	2	2	2	2
aim(s) clearly stated?	2	2	1	2	2	2	2	2	2	2
ethical issues addressed?	1	1	0	1	1	1	0	0	0	1
Quantitative questions on methodology										
Is the study design and rationale evident?	2	2	2	2	2	2	2	1	2	2
experimental hypothesis?	0	1	2	2	2	1	2	0	2	2
Are the key variable defined?	2	2	1	1	1	2	2	2	2	2
Is the population identified?	2	2	2	2	2	2	2	2	2	1
Is the sample described and reflective of the population?	0	1	0	1	1	0	1	1	1	1
data collection valid and reliable?	1	1	0	1	1	1	1	0	1	1
data analysis valid and reliable?	2	2	2	2	2	2	2	2	2	2
estimate of variance?	2	2	2	1	2	1	0	2	2	2
confounding variables?	2	2	0	0	2	2	2	1	2	1
Results and discussion quality checks										
results presented clearly?	2	2	2	2	2	2	2	2	2	2
discussion comprehensive?	2	2	2	2	2	2	2	2	2	2
conclusion comprehensive?	1	1	1	1	1	1	1	1	1	2

Quality rating scores for the qualitative studies

Study	K	L	M	N
Does the title reflect the content?	1	2	2	2
Are the authors credible?	2	2	2	2
Does the abstract summarise the key points?	2	2	2	2
Is the rationale for undertaking the research clearly defined?	2	2	2	2
Is the literature review up to data and comprehensive?	1	2	2	2
Is the aim(s) of the research clearly stated?	2	2	2	2
Are ethical issues identified and addressed?	0	2	0	1
Qualitative questions on methodology				
Are the philosophical background and study design identified and rationale for choice of design evident?	0	2	0	0
Are the major concepts identified and defined?	2	2	2	2
Is the context of the study outlined?	1	2	1	1
Is the selection of participants described and sampling method identified?	1	1	1	2
Is the data collection method clearly described and systematic?	2	2	1	2
Is the data analysis clearly described and systematic?	2	2	1	2
Use of verification procedures to establish credibility?	2	2	1	2
Reflexivity account provided by the researcher	0	1	0	0
Results and discussion quality checks				
Are the results presented in ways that are appropriate and clear?	2	2	2	2
Is the discussion comprehensive?	2	2	1	2
Is the conclusion comprehensive?	1	1	1	1

Appendix 6: Stages of data synthesis (Aveyard, 2010) (Chapter 1)

Stage 1: Summary of information

- A Meta summary was produced to develop a good understanding of each study.

Stage 2: Integration and interpretation phase

- The results of each study were compared and contrasted.
 - Codes were assigned to the main findings and discussion points.
 - The codes were grouped to identify emerging themes
 - The codes and themes were revisited to check that the codes best fit their theme and that all codes had been assigned to a theme.
 - The themes were further scrutinised to look for patterns, similarities and differences across the different studies.
-

Appendix 7: Additional participant demographic details of studies included in the literature review

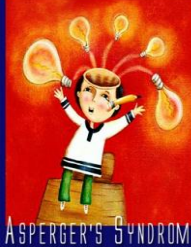

Study	Ethnic status	Employment status	Marital status	Religious affiliation/preference	Education level	Income
Alferi, Culver, Carver, Arena & Antoni, 1999	All Hispanic women	(%) Employed 21.0 Retired 14.0 Unemployed 65.0	Not stated	(%) Catholic 72.5 Evangelical 23.5 Jehovah Witness 5.0 Evangelist 4.0 Pentecostal 1.0 Baptist 1.0	Not stated	(% yearly income) Less than \$8000 70
Culver, Arena, Antoni & Carver 2002	(N) Sample 1 Non Hispanic 70 Hispanic 4 African American 1	(N) Sample 1 Employed 47 Retired/ or currently not working 28 Sample 2 Employed 13 Retired/ or currently not working 43	(N) Sample 1 Married or equivalent relationship 53 Sample 2 Married or equivalent relationship 20	Not stated	Sample 1 14.63 Years of education (mean) Sample 2 9.04 Years of education (mean)	Not stated

Ebright & Lyon 2002	(%) Caucasian 100	Not stated	(%) Single 37 married 73	Not stated	(%) Did not attend College 47 Attended College 53	(% yearly income) Less than \$50,000 44 More than \$50,000 66
Feher and Maly 1999	(%) Caucasian 73.0 African American 15.0 Asian 6.0 American 6.0 Latina 6.0	Not stated	(%) Married 49.0 Widow 27.0 divorce/separated 24.0	(%) Protestant 53.0 Catholic 16.0 Jewish 19.0 Other 12.0	(%) less than high school 12 College Level 73 More than college 18	(% yearly income) Less than \$15,000 33 \$15,001 -45,000 43 \$45,001-100,000 24
Gall, Charbonneau & Florack, 2011	(%) European 96.8 Canadian 2.2 Asian 1.1 Hispanic 0 Black/other 0	(%) Employed 36.7 Retired 48.4 Unemployed 14.0	(%) Single 7.5 Married 66.7 Divorced 11.8 Widowed 14.0	(%) Protestant 36.6 Catholic 44.1 Jewish 2.2 Muslim 0 Other Christian 2.2 None 11.8 Other religion 1.1	Not stated	Not stated

Gall, Guirguis-Younger, Charbonneau & Florack, 2009	Cancer group %	Cancer group %	Cancer group %	Cancer group %		Not stated	Not stated
	European	Employed 36.7	Single 7.5	Protestant 36.6			
	Canadian 96.8	Retired 48.4	Married 66.7	Catholic 44.1			
	Asian 2.2	Unemployed 14.0	Divorced 11.8	Jewish 2.2			
	Hispanic 1.1		Widowed 14.0	Muslim 0			
	Black/other 0			Other Christian 2.2			
				None 11.8			
				Other religion 1.1			
	Benign group %	Benign group %	Benign group %	Benign group %			
	European	Employed 63.7	Single 12.5	Protestant 42.0			
	Canadian 93.8	Retired 26.2	Married 70.6	Catholic 42.7			
	Asian 1.9	Unemployed 9.3	Divorced 10.7	Jewish 0.6			
	Hispanic 0.6		Widowed 6.2	Muslim 0.6			
	Black/other 1.9			Other Christian 1.3			
				None 11.5			
				Other religion 1.3			
Herbert, Zdaniuk, Schulz & Scheier 2009	(%)	Not stated	Not stated	(%)	(%)	Not stated	
	White 88			Protestant 44.0	attended college		
	African			Catholic 39.0	72		
	American 10			Jewish 5.0	vocation trade school		
	Hispanic or			Other religion 6.0	6		
	other 2			no religion 5.0	graduated high school		
					21		
					not completed high		
					school		
					1		

Jim, Richardson, Golden-Kreutz & Anderson, 2006	(%) White 92 Hispanic 1 African American 7	Not stated	Not stated	Not stated	(%) Less than 12 years 3 12 years 23 13-15 years 27 16 years 19 More than 16 years 9	(% yearly income) Less than \$15,000 6 \$15,000 -29,000 15 \$30,000-49,000 20 \$50,000 -79,000 2 More than \$80,000 29 Declined 7
Landmark, Strandmark & Wahl 2001	Not stated	(N) Teacher 4 nurse 3 sick benefit 3	(N) Married 7 cohabit 1 Divorced 2	Not stated	Not stated	Not stated
Northouse 1989	Not stated	Not stated	Not stated	Not stated	Approximately 13-14 years of education	Not stated
Pedersen, Christensen, Jensen & Zachariae 2013	The sample was considered to be nationally representative with respect to disease and treatment related variables.					


Stanton, Danoff-Burg & Huggins, 2002	(N)	Not stated		Married or equivalent relationship N = 49	Not stated	14.18 Years of education (mean)	Not stated
	White 64						
	African American 5						
	Latino 1						
Teleghani, Yekta & Nasrabadi, 2005	All Muslim women	(N)	Housewife 17 other 6	(N) Married 17 Single 1 Divorce 1	Not stated	Not stated	Not stated
Thunè-Boyle, Stygall, Keshtgar, Davidson & Newman, 2013	(%)	(%)	(%)	(%)	(%)	14.9 years of education (Mean)	Not stated
	Caucasian 82.6	Employed 58.7	Single 14.9	Protestant 44.5			
	Black 4.5	Retired 28.4	Married 44.8	Catholic 23.2			
	Oriental 1.9	Housewife 10.3	Living with partner 6.5	Jewish 7			
	Other 7.1	Unemployed 2.6	Separated 5.8	Hindu 1.9			
	Asian 3.9		Divorced 16.2	Muslim 2.6			
			Widowed 11.7	Buddhist 1.9			
				None 16			
				Atheist 2.5			



Participants wanted!

Are you a parent? YES
Did your son/daughter receive a diagnosis of
Asperger's Syndrome in adulthood? YES

we need you.



This research aims to explore the experiences of
parents who cared for their son/daughter who
received a diagnosis of Asperger's Syndrome in
adulthood

What it will involve: You will be asked to take part in an
interview with the main researcher.

Where: ASPIE Wednesday drop in group

To take part or for further information
please contact:
Main Researcher: Gurmeash Kaur
Tel: 07806631270
Email: kaurg19@uni.coventry.ac.uk

Appendix 9: Ethical Approval received from Coventry University

A qualitative study exploring the experiences of parents' whose child did not receive a diagnosis of Asperger's Syndrome until adulthood P2418

REGISTRY RESEARCH UNIT
ETHICS REVIEW FEEDBACK FORM
(Review feedback should be completed within 10 working days)

Name of applicant: Gurmeash Kaur

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: A qualitative study exploring the experiences of parents' whose child did not receive a diagnosis of Asperger's Syndrome until adulthood

Comments by the reviewer

1. Evaluation of the ethics of the proposal:
This is a generally sound proposal from the perspective of ethical requirements. In response to the question about funding, the applicant lists herself as funding the research, however, this should say Coventry University (Clinical Psychology Doctorate Course).
2. Evaluation of the participant information sheet and consent form:
The Consent form is clear and appropriate.
The Participant Information Sheet is appropriate, though a few minor changes are suggested as follows:
1. Under heading "What is the purpose of the study?", replace "...cared for their child without them receiving a formal diagnosis..." with "...cared for their child who did not receive a formal diagnosis..."
2. Under heading "What are the potential disadvantages of participating?", replace "If this is likely to distress you" with "If you think that this is likely to cause you significant distress."
3. Under both the heading "Do I have to participate?" and the heading "What are the benefits of participating?", please indicate a time limit by which individuals can request to have their data withdrawn from the study, as this will not be possible once the data analysis has been completed. I suggest that the applicant indicates a date approximately 3 months before the final submission date for their research study.
3. Recommendation: (Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).
<input type="checkbox"/> Approved - no conditions attached
<input checked="" type="checkbox"/> Approved with minor conditions (no need to re-submit)
<input type="checkbox"/> Conditional upon the following – please use additional sheets if necessary (please re-submit application)
<input type="checkbox"/> Rejected for the following reason(s) – please use other side if necessary
<input type="checkbox"/> Not required

Name of reviewer: Anonymous.....

Date: 18/03/2013.....

Gurmeash Kaur Page 1 of 1 19 March 2013

Appendix 10: Gatekeeper letter, email response from ASPIE and ethical approval received from Coventry University regarding participant recruitment from ASPIE

Gatekeeper Letter

03/05/2013

ASPIE
29 Samsone Way
Worcester
WR1 1LX

Dear Ben Say

My name is Gurmeash Kaur and I'm currently beginning a research project for my Clinical Doctorate course at Coventry and Warwick University.

Subject to approval by Coventry University Ethics this study will involve interviewing parents of children who were diagnosed with Asperger's syndrome in adulthood.

This study aims to explore the experiences of parents whose child did not receive a diagnosis of Asperger's Syndrome until adulthood.

The key question is:

- How did parents cope with the difficulties of raising a child without the diagnostic label Asperger's Syndrome?

Specifically, the researcher aims to explore the following areas:

1. How did parents cope without the support of services for people with Asperger's Syndrome?
2. What (if any) stresses did parents encounter raising a child without a diagnosis of Asperger's Syndrome.
3. Issues around misdiagnosis
4. How did the absence of a diagnosis of Asperger's Syndrome effect the parent's relationship with their partner and their son/daughter?
5. How did parents feel towards health professionals?
6. What services do parents think should be in place to address their needs?

I'm writing to ask your permission to be allowed access to the individuals who access ASPIE. The interviews will be conducted at a convenient time and date, which will be arranged with the participant and conducted on the ASPIE site. All interview recordings will be saved on a password protected computer and anonymised. All participant information will be kept strictly confidential and the results will hopefully be reported in a research paper available to all participants on completion.

If this is possible please could you E-mail me at kaurg19@uni.coventry.ac.uk to confirm that you are willing to allow me to contact individuals that access ASPIE to invite them to take part in my research.

Yours sincerely

Gurmeash Kaur

Email received from ASPIE following gatekeeper letter

From: Abi Coward <abi.aspie@outlook.com>

Sent: 18 May 2013 13:52

To: Gurmeash Kaur

Subject: RE: research participants enquiry

Dear Gurmeash,

I have read the attached letter and can confirm that we (ASPIE) are still happy to be a part of your research as outlined in the letter. We look forward to seeing you!

Kind Regards

Abi

Abi Coward

Volunteer & fellow Aspie!

ASPIE Ltd. Charity No: 1145351

www.aspieeverywhere.org

Ethical Approval received from Coventry University for recruitment from ASPIE

Step	Status	Authoriser	Authorised on
Supervisor	Approved	Jo Kucharska	Wed, 22 May 2013 04:17 PM
Referrer	Not required		
Reviewer	Not required	Reviewer	
Finalizer	Approved	Elaine Cartmill	Thu, 23 May 2013 07:40 AM

A qualitative study exploring the experiences of parents' whose child did not receive a diagnosis of Asperger's Syndrome until adulthood
P2418

REGISTRY RESEARCH UNIT ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Gurmeash Kaur

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: A qualitative study exploring the experiences of parents' whose child did not receive a diagnosis of Asperger's Syndrome until adulthood

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

2. Evaluation of the participant information sheet and consent form:

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

☐

Approved - no conditions attached

☐

Approved with minor conditions (no need to re-submit)

☐

Conditional upon the following – please use additional sheets if necessary (please re-submit application)

☐

Rejected for the following reason(s) – please use other side if necessary

☒

Not required

Name of reviewer: Anonymous.....

Date:

Appendix 11: interview schedule

Interview Schedule

1. What was life like raising/caring for your child who did not receive their diagnosis of Asperger's syndrome until adulthood?
 - What effect (if any) did it have on the family?
 - What effect (if any) did it have on your relationship with your partner?
 - How (if at all) has it affected your relationship with your son/daughter?
2. What stresses did you encounter raising your child?
3. What was your experience of issues encountered on your route to your child's diagnosis?
 - Was your child misdiagnosed and if so what effect did this have?
 - Were they given any treatment and what effect did it have?
4. How would you describe your experiences of health professionals you had contact with?
 - Did you feel listened to, understood?
 - Feelings - sad, angry, upset, happy
 - Were they sympathetic?
 - did you notice that your child may be different to other children?
5. How did you feel once your child received the diagnosis 'Asperger's syndrome'?
6. What services do you think should be in place to meet the needs of parents?

Appendix 12: Participant information sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

THE UNIVERSITY OF WARWICK

Coventry University

Participant Information

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

Parent's experiences of caring for their child who did not receive a diagnosis of Asperger's Syndrome until adulthood.

What is the purpose of the study?

The aim of this study is to explore the experiences of parents who have cared for their child who did not receive a formal diagnosis of 'Asperger's Syndrome' until adulthood.

Why have I been chosen to participate?

To take part in this study you must be a parent to an individual who received a diagnosis of Asperger's Syndrome in adulthood.

Do I have to participate?

No. Participation is entirely voluntary. The information you provide will be kept anonymous, which means that it will not be able to be traced back to you. If you later decide that you do not wish to have your information included in the study, you can withdraw your data within 2 weeks of the interview by emailing the main researcher, Gurmeash Kaur at the email address provided below. You do not have to state your reasons for withdrawing your information and it will not affect any ongoing or future services from the National Health Service or any other service.

What do I have to do?

You will first be asked to complete some questions regarding you age, sex and age at which your child was diagnosed with Asperger's Syndrome.

You will then be asked to take part in an interview with the main researcher. The interview will consist of questions exploring your experiences of caring for your child and the effect it has had on you as a parent. You will be provided with an interview schedule before the interview, so you know what questions will be asked.

Data storage and confidentiality

All information you provide will be stored in a locked cabinet which only the main researcher will have access to.

The interview will be digitally recorded and later transcribed by the main researcher. The audio file will be stored as a password protected computer file and destroyed once it has been transcribed. During the transcription process any identifying information will be

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

removed. The researcher may use extracts from the interview in the final research article, these extracts will be anonymised.

What are the potential disadvantages of participating?

The study will require you to volunteer approximately 1 hour of your time. Some individuals may find some of the questions sensitive. If you think this is likely to cause you significant distress please do not participate.

What are the benefits of participating?

The research is aimed to be published and therefore contribute to the minimal literature of exploring family member's experiences of the issues surrounding an adulthood diagnosis of Asperger's Syndrome. By taking part in this study you will also gain an insight into how qualitative research studies are conducted. If you wish to have your data withdrawn from the study you can email the main researcher within 2 weeks of your interview at the email address provided below.

What if things go wrong?

If you are not satisfied with any part of this study or the conduct of the researcher, you can make a complaint using the complaints and compliments section on the Coventry University website. If you wish to have your information withdrawn from the study you can email the main researcher, within 2 weeks of your interview at the email address provided below. You do not have to state your reasons for withdrawing your information and it will not affect any ongoing or future treatment received from the National Health Service Care or any other service.

What will happen with the information I provide?

The information you provide will form the results and discussion part of the study. This will be written up as part of a doctoral thesis. It is also hoped this study will be published in a peer reviewed Journal. If you wish to receive a copy please email the main researcher, Gurmeash Kaur (email address below).

Who has reviewed this study?

This study has been reviewed and approved by Coventry University ethics department.

Contact details for further information


Main researcher: Gurmeash Kaur
Email: kaurg19@uni.coventry.ac.uk
Clinical Supervisor: Dr Tim Lacey
Email: Tim.Lacey@hacw.nhs.uk

Appendix 13: Informed consent sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Informed Consent Form.

Summary information about research

This study aims to explore the experiences of parents who have cared for their child who did not receive a diagnosis of Asperger's Syndrome until Adulthood.

Please Initial in each box

1. I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw my information within two weeks of participating without giving a reason. Furthermore, this will not affect any ongoing or future treatment I may receive from the National Health Service or any other service. ☐
3. I understand that all the information I provide will be treated in confidence. ☐
4. I understand that I have the right to change my mind about participating in the study at anytime during the interview or after. I can do this by contacting the main researcher. ☐
5. I agree to this interview being recorded for analysis purposes and understand the audio recording will be stored on a computer which will be password protected. The recording will be deleted once transcribed by the researcher. ☐
6. I agree to take part in the research project ☐

Name of participant:

Signature of participant:

Date:

Witnessed by (if appropriate):.....

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
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1

Name of witness:

P.T.O

Signature of witness:

Name of Researcher:

Signature of researcher:

Date:.....

Appendix 14: Debrief Sheet

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Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D, CPsychol

THE UNIVERSITY OF
WARWICK



Parent's experiences of caring for their child who did not receive a diagnosis of Asperger's Syndrome until adulthood.

Thank you for taking part in this study. Your participation is much appreciated and I hope you found the interview process interesting and insightful.

Please remember if you later decide that you do not wish to have your information included in the study, you can withdraw your data within 2 weeks of this interview by emailing the main researcher, Gurmeash Kaur at the email address provided below. You do not have to state your reasons for withdrawing your information and it will not affect any ongoing or future services from the National Health Service or any other service.

If you have felt distressed or upset by anything that we have talked about today, please contact Dr Tim Lacey, who will arrange a time to discuss any arising issues with you.

If you were unhappy about any part of the interview process you can make a complaint using the complaints and compliments section on the Coventry University website.

Contact Details

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Coventry and Warwick Clinical Psychology Doctorate Course
Coventry University
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Dr Tim Lacey

Worcestershire NHS health and care trust.

Adult Mental Health Team

Redditch, Worcestershire

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Appendix 15: Guidance for data analysis (Smith, Flower & Larkin, 2009

p. 82- 103)

Step 1: Reading and re-reading

- Immersing oneself and actively engaging with the data

Step 2: Initial noting

- Exploratory examination of the semantic content and language use, guided by the following three stages.
 - a. Descriptive comments – describing the content at face value to understand the participants' world.
 - b. Linguistic comments – focusing on the way the content is presented. For example considering the use of laughter, repetition etc.
 - c. Conceptual comments – this involves an interpretative level of analysis, which requires a shift of focus towards understanding the participant's world. Interpretations arise from attentive attending to the participant's words.

Step 3: Developing Emergent themes

- This stage is marked by an analytic shift, as the researcher begins to mainly work with the notes from step 2 rather than the transcript.
- Exploratory notes are analysed for connections, patterns and interrelationships.
- Themes reflect the participant's words and the researcher's interpretations.

Step 4: Searching for connections across emergent themes

- Analysing how the emergent themes fit together
 - The development of super-ordinate themes. This is done by clustering similar
-

themes together and giving them a super-ordinate theme title.

Step 5: Moving to the next case

- Carry out steps 1-4 for all cases
- Treat each case as individuals and bracket ideas emerging from earlier analysed cases

Step 6: Looking for patterns across cases

- Identify themes which are most important, look for connections across cases
 - This step may lead to reconfiguring and re labelling of themes.
-

Appendix 16: An example of part of a coded transcript using IPA

Transcript 1: Female, 69 years old. Son diagnosed age 20. Now 33.

Comments, summaries	Transcript	Themes
everyday life not easy I suppose as aspergers second child, stressful 6 wks pregant - had 2 mcs I was in Devon in sell house buy house. Had 18 mths year old pregnant, hospital blood pressure, 11 days moved house	I) What was everyday life like raising your child who did not receive their diagnosis until adulthood? P) Everyday life, It was <u>not easy for a lot of reasons</u> . Apart from I suppose the Aspergers, because he was my second child I already had a little girl. And he was <u>stressful having him</u> . I was 6 weeks pregnant with him when my husband got moved jobs. So <u>I was in Devon and he was in Southampton</u> . We had to sell the house in Devon and buy a house in Southampton. And I had a 18 month year old and I was pregnant and I was taken to hospital with blood pressure in the end. So things didn't get. So when he was 11 days old we moved house I) Again P) No to Southampton. We did the whole thing while I was pregnant. So <u>I ended up with a toddler a brand new baby and a house in a place I didn't know anybody and so it was a lot and erm he was a very good baby</u> . But he was so different from my daughter. And <u>I don't know what stage I knew because I actually from a nursing background and I did paediatric nurses</u> . And I nursed babies. So <u>I knew about how babies behaved and that kind of thing</u> . I knew he was different he was very quiet. And has he got older he didn't do the things I expected him to do I) And about what age was this? P) Well he was 18 months when he got his chalk and wrote the letter A and he didn't play run around. He learnt to speak but that was ok. But he wanted when he got to about 3. He liked the books he had an alphabet book and he would go right though and then he turned into reverse and went back again. He did that with loads of things he would do it and reverse it. So by the age of three he knew his alphabet and he could count to ten forwards and backwards. Technically he's not supposed to do. But he learnt it and he became obsessed. And we went on holiday to Wales he would do drawing but he wouldn't draw pictures he would write alphabet letters over and over again. He would do them in capitals, block	Life not easy stressful pregnancy. - none had 2 move stressful time selling / buying house - ended up with a blood pressure <u>Doing things on our feelings instead.</u> Overwhelming time. -> A lot to deal with at once. Good baby, so different from my daughter. - used previous knowledge from own background. - different. <u>mother's intuition</u> not a normal child. <u>Did extraordinary things</u> did things over and over Obsessed nature. <u>level of pride could do what others couldn't.</u> Not do normal things "not draw not alphabet letters - over and over."

<p>write them in different ways, - never draw pictures much was odd.</p> <p>obsessed to road signs merged, writing as a middle it was as road sign, knew name of sign.</p> <p>one so took after him - I'm on a course.</p> <p>sniffing, cup of tea</p> <p>granny's sign</p> <p>granny freaked out -</p> <p>4 spelling words</p> <p>he would over - full sentences.</p> <p>dropped daughter school - bus - about showing him flash cards, no I'm not</p> <p>wasn't really,</p> <p>he was repetitive, road sign</p> <p>gently, cartis,</p> <p>is he genius or not - I don't know</p> <p>exhausted to pregnancy, moving house didn't take notice.</p> <p>Perhaps I ought to.</p> <p>bed down, weepy woman +</p> <p>verdict of mother,</p> <p>her mother doesn't like sort of broke me</p> <p>granny came, my husband can't, shouldn't have told me.</p> <p>he had been put to bed -</p> <p>grandmother said, husband</p> <p>ok - slammed door - not good</p> <p>'well' was awful, I was in</p> <p>'ear'</p> <p>He was vulnerable - I know</p> <p>he wanted to be with me</p> <p>gone through one door - out another - he thought</p>	<p>capitals, fancy script, he would do them digital form endlessly but I never saw him draw a picture, which was very odd. Then he became obsessed with road signs, when he was three we moved to Hereford and I was working as a midwife and it was the road signs he could he knew the name of things. I went away and granny looked after him for a few days cos I went on a refresher course and there is a shop in Hereford called Wakefield knight, knight as in knight. And they went around town shopping, sat and had a cup of tea and did all the granny things and he went back home and he got letters out and and he made Wakefield knight across the kitchen floor and granny freaked out.</p> <p>I) Ok</p> <p>P) So by the time he was four. He got to the stage of spelling words. He would say can we go to the bus stop please. I'm going to get a colt and then I think we will go home. And I had parents at the school bus where my daughter went to school. You know your showing him flash cards. No I'm not it was embarrassing it was awful. It was weird really and yet he didn't play very much and he was repetitive and he liked his road signs and things like that. And there he was with all this spelling and writing. And I was like is he a genius or what and I hadn't got an idea. At the time I was not particularly. When I got to Hereford I was exhausted with the pregnancy and moving houses and perhaps I ought to. I was a bit down and I was a bit weepy, you know so I wasn't the perkier mother at the time. What else can I say? But there was time when he was very, it sort of touched me. When I went on this course. And granny had come in and my husband was there. They shouldn't have told me. I wish they hadn't but he was in his bed and he had been put to bed. And grandmother was on the landing and husband went out to get something from the car and he went out and slammed the front door and granny said 'oh no not you as well', which was awful. I was in floods of tears. I know it was things like that so he was sort of vulnerable and I know once I was trying to get to the shower because something was happening and he wasn't sleeping and he wanted to be with me and I had gone through one door but out into another and he thought.</p>	<p>odd not to do normal things</p> <p>road signs obsession</p> <p>I know - mother's notion</p> <p>- absence of father - granny looked after him</p> <p>- emphasizes normal things to do as expected.</p> <p>granny freaked out</p> <p>over: expectations of him</p> <p>Age 4 full sentences.</p> <p>- showing off, showing off how smart he is</p> <p>one people's perceptions</p> <p>one feeling embarrassing & awful.</p> <p>weird feeling,</p> <p>child repetitive.</p> <p>confront him out is no</p> <p>a genius - don't know</p> <p>- self blame, didn't take</p> <p>if notice.</p> <p>feeling depressed.</p> <p>not perkier mother - idea</p> <p>not good enough mother?</p> <p>'touched me'</p> <p>- re telling of story,</p> <p>husband slammed car</p> <p>door - granny said</p> <p>"oh no not you as well"</p> <p>I was in floods of</p> <p>tears - bed down in my</p> <p>life.</p> <p>vulnerable individual.</p> <p>↓</p> <p>longing to be with me.</p> <p>↓</p> <p>waited for me laying</p> <p>sleep at as door - pity him</p> <p>didn't call me</p> <p>HE NOT PRODIGE A SENSITIVE ISSUE.</p>
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- crawled, followed me sleeping next to door - as if waiting for me but didn't ask.
I have to mention it breast feeding only.

got hold of my nipple between gums, pulled head back as far as could go & looked at me & laughed.
- never went on it again

reading a book - he was in one side of table - put one of his feet flip.

played at playgroup said he has autism.

query started early, observed - sat in corner, spun wheels, not with other children.

think autistic - nurse at playgroup - knew about mental closure autism I said I don't think he can write letters.

lear my desk, I'm getting on.

made app't a paediatrician - had medical student - noisy off - used himself, curling up - didn't want to be seen.

I said yes, perhaps attended paediatrician - sent him on a day, physical exam - like a beetle, wasn't nice, about 4

He crawled and followed me and lying sleeping next to this door because he thought as if he was waiting for me but he didn't ask. And the other thing which I just have to mention I stopped breast feeding. It was different I sat down to breast feed it was about Easter and he was the previous July so I had fed for quite a long time. I put him on and he sort of had a little go and then he got hold of my nipple between his gums while I was holding him. He pulled his head back holding his nipple as far as he could go and he looked up at me and laughed. That was a funny thing to do and then he turned his face away and he never went on it again but it was so you know a sense of humour.

I) Yes

P) To do that, whatever age. And once I was reading a book and he was on the other side of table and just put his finger in it and went flip. You know little things like that. Then he was queried when he went to play group and they said query he had autism.

I) So it started quite young then

P) Well yes with the query, that was a very observant lady, he sat in the corner and spun wheels and didn't bother with the children.

I) Right

P) I got a visit from a health, social worker I suppose she was. She said we think he is autistic. Now as a nurse from paediatrics I only knew about conventional classic autism. And I said I don't think he is he's here writing letters and he could also write reverse alphabet. [inaudible] So I said I don't know and she said I've got to clear my desk because I'm getting married. She was clearing her desk to leave it for someone else. She made an appointment with some paediatrician and we went and I. He was, he had a medical student with him and was busy showing off to him and he wasn't particularly off and BC buried himself and he was curling up as if he didn't want to be seen. And I said I'm ever so sorry about this. Perhaps he offended the paediatrician anyway. He kind of sat him on a thing gave him a physical examination like he was a beetle. He wasn't particularly nice to him. He was about 4 and said

sense of pride again

subconscious level - repent her closeness with him. breast feeding.

playgroup won't nipple - one feels as humour, laughed at me.

- concrete thinking
able to see pointers in other child.

more wary his humor - but one could also have been seen on as malicious.
query off early stage.

oppressed by others.
VERY observant lady.
first signs of autism

lack of knowledge of AS.

- told autistic - as a nurse only knew about emotional autism
- maybe one feel denial didn't want to hear it.

- nurse was busy.

- went to see a paediatrician first significant encounter with HP.

- son scared, buried himself curling up, didn't want to be seen. - Asperger's more offended.

- gave physical examination
- like he was a beetle.

metaphorical - small hard, sturdy can take it - ungracious like an insect.

<p>no my way, socially didn't have any do front - I was depressed felt just like a creep not one not he did - didn't + violent AS out was out</p> <p>started school - went in school bus, catholic school, - go see do headmaster 2 weeks - merge seg see headmaster - not fit to be in school - be banned</p> <p>Come home 2 wet pants - teachers or hard time - distressed</p> <p>sitting in tears - didn't - even say do you have any problem - imply my have started / needed help, baring in - daughter - apple of his eye</p> <p>at school could read / write - pencils for letters in family</p> <p>read way and endive - thought he was wonderful son - that reads.</p> <p>son - age 5 - headmaster unfortunate - over one couldn't sell his house second choice -</p> <p>on night - I went back to work - problem school - saying he not fit to be there.</p>	<p>there is nothing wrong with him he's fine, go away. And I didn't have the thing to fight because I was depressed. I just felt put down and sort of crept away. I wasn't sure what he did and I didn't understand about aspergers. So that was that.</p> <p>- lack of AS knowledge.</p> <p>P) Then he started school and after 2 weeks it was a school where you went on the school bus. It was a catholic school. And after 2 weeks I got a message saying will you go see the headmaster. And he said well erm. He's not fit to be in school and he's going to be banned if his behaviour doesn't improve. I thought what the hell. It was so offensive. It transpired and he must have come home with some wet pants he was wetting and he was giving the teacher a hard time and he couldn't even hold a pencil. He was obviously absolutely distressed as anything. And I was just sitting there outside, I was in tears it was just so [inaudible] he didn't even say do you have any problems with him at home. Or how is he with... they just said he's not fit to be in school and we are thinking of banning him, unless he gets [inaudible] charming and my daughter had been the apple of this teachers eye because she had arrived at school being able to read because we seem to have a facility for letters and reading in our family. So she could just read and when I said to them she can read. They said no she just understands she knows it off by heart he said. So she went in and read her way through the entire [laughter] so that teacher thought she was wonderful and yet my son being treated like you know like shit really.</p> <p>I) How long ago was that</p> <p>P) We're talking 1980's, 1984 he was about 5. And that was a very unfortunate headmaster at that time. They had intended to have another one he was the second choice. The first choice couldn't sell his house in the north so we got lumbered with this one. He was notorious everyone knew he was a... anyway.</p> <p>P) Than school he just never sought of. I can't remember because I was on nights at this time. I was working back as a midwife cos I had got them to school. This problem with them saying they were gonna ban him and he was not fit to be there. The school nurse was there and she</p>	<p>negative deeply experience with paediatrician - didn't fight, depressed crept away - upset, in - significant</p> <p>- After 2 weeks school teachers finding him difficult</p> <p>- not fit to be in school - banned - offensive -</p> <p>- meeting - was he stressed. - distressed.</p> <p>- couldn't hold a pencil</p> <p>- school may have a different perception - not empathic!</p> <p>- awful, distressing experience encounter in school - I was in tears.</p> <p>- Is not offering help - on our own you sort it out.</p> <p>- Comparison in other children</p> <p>- pride of a mother.</p> <p>- teachers thought I was exaggerated - she showed them - attitude.</p> <p>- son treated like second class.</p> <p>- second choice - second class.</p> <p>- excuse for no teacher.</p> <p>- he just never sought of fit in - difficult for mother to say - I started from memory</p> <p>on night - not sure!?</p>
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<p>School nurse said family unit - maybe help dem over next morn'g altho in corridr - in tears social worker - saw saint and on. - saw child therapist - Freudian - go into play therapy. - do children nurse see's social worker don't know how happened - normally see no G.P. see therapist x 2 a week. quite one one Nobody A.S or autism -</p> <p>not picked up</p> <p>most so ordinary school catchy second teacher good</p> <p>used to tell jokes - kids roar & laughter BC understands doesn't get them. - good teacher etc - ran few m-e.</p> <p>bullied distressed I didn't know Your mother boy being bullied - first time I realised</p>	<p>said there is a family unit you can go to. Ermm so perhaps go see them maybe they could help you lot. And I thought right and I was down there the very next morning sitting in their corridors in tears and the social worker gave a long in and she sort of saw the saint and the sin and so I went to see her and they set up they had a child therapist there she was Freudian and she would sit him you know how they go into play therapy and do whatever they want and the mother sees the social worker kind of thing. I don't know how it happened cos normally I would see the GP and there we where and he was seeing this child therapist twice a week, which he did for quite a time. And nobody ever mentioned aspergers or autism. Whatever but this woman was on a different plane I suppose. And she did help him and calm him and I think he. But in the end she stopped seeing him and I suppose she didn't quite know what to make of him. But erm I mean no recognition. But now and after wards I thought flippin heck.</p> <p>I) And it wasn't picked up then</p> <p>P: no</p> <p>I) So he stayed at school</p> <p>P) Yes he went to ordinary school. He was catchy and the second teacher was very good. He got on well with her and I remember her saying to me. she used to tell me funny stories and jokes to the kids and they all roar with laughter cos they know it's a joke but she said that I can tell BC understands them and erm and BC really understand the joke but he's really laughing. She was you know you have a good teacher and then a few more so on and so forth.</p> <p>P) He got bullied at school as well, which distressed me a lot at that time/. And I knew both who it was but I didn't know until I Can't remember who it was...at the school gates and mother said your mother of the boy who is being bullied aren't you and that was the first time I realised it was happening.</p> <p>I) Right</p> <p>P) I thought fair enough and went in and saw somebody</p>	<p>School nurse - helped, after something</p> <p>parenting? "saint and sin"</p> <p>- saw child therapist. - second encounter. do whatever they want - little understanding ↓ Kenny don't know how I got it. - no recognition of AS or autism - reasm = Freudian</p> <p>- didn't understand him - hindsight = "flippin heck"</p> <p>catchy?</p> <p>all our kids "roar" & laughter not BC - smaller I didn't see it - metaphor. ↓ get the joke but not laugh to some element of denial did he get the joke??</p> <p>- difficult upbringing from - distressing for parent</p> <p>- Told by another parent at school gates not on.</p>
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Appendix 17: An example of the organising and clustering of the emergent themes for one of the participants

Mary connecting themes

- **Lack of understanding**
 - Frustration at not being able to understand child's behaviour - mother felt a failure as a result
 - Parenting as if child's is 'normal'
 - Child's behaviour was a mystery however parents had an urge to understand
 - Child was 'written off' by teachers because could not understand child's behaviour
 - Autism was seen as a foreign concept
 - Child had a desire to understand themselves
 - Even though parent was surrounded by friends nobody knew the child's difficulties – hidden disability

Comments	Participant Quotes
1. Parenting child with AS frustrating	Frustrating, straight away. Yes frustrating
1. Parenting child with AS isolating – others not understanding/ashamed what others might think	I would also say isolating
1. Child unable to understand mother – mother felt couldn't communicate with own son	He wouldn't, tended not to understand I can remember simple things at home.
2. Child's behaviour seen as a mystery to parents - had a desire to understand	we had many many discussions I guess me and his dad and other people discussed why this apparently intelligent child was struggling with the simple things in life.
2. Frustrating for parents seemingly intelligent child could not understand simple instructions	But seemingly understanding simple things we would ask him. He just didn't seem to grasp
3. Son written off – no hope – difficult for mother to hear	a maths teacher who said Mr and Mrs X I don't know what more to do, how to teach or where to go with your son because I think he is un-teachable.really concerned me.
4. Child had a desire to understand themselves	Come home very frustrated and say mum, dad I need to know.
5. Unaware of existence of autism	I was not aware in any way about

	autism.
6. Even though others around still a feeling of isolation – child not talked about seen as embarrassing	even so it still felt isolating because obviously nobody me and his dad
8. Didn't know how to parent seen as a weakness - in the dark, alone	perhaps it was weak of me but when I used ring up his dad but I just didn't know what to do and I felt desperate.... I felt lonely and isolated
8. AS – unknown entity how can people help	Didn't know anything really about autism back then certainly not Asperger.
11. Other people (family) couldn't understand his behaviour	My mum had to say I don't know X you know and her name was X. He didn't need changing, he wasn't thirsty, he wasn't too warm he just didn't sleep
11. Emphasis on I don't know - still struggling to understand own child	I don't know if he just doesn't need sleep or it's his brain. I don't know or his body. I don't know.

- **Parent described feeling that her child did not fit in 'not normal' and always knew something was not quite right**

- **Mothers intuition**

Comments	Participant Quotes
1. Child did not 'fit in'	because P didn't fit in, he didn't seem to be like other children
1. Child did not behave in the normal way. Seen as different 'abnormal'	Nursery...he would read books instead and he would tend to not interact I noticed with other children ...why does this child seem to behave differently.
6. Parents not surprised at diagnosed always knew their child different	Like I said we always knew there was something but not knowing what.

- **Death of the normal child**

- **Reality of not having the normal child**

Comments	Participant Quotes
1. Child did not behave in the normal way. Seen as different 'abnormal'	Nursery...he would read books instead and he would tend to not interact I noticed with other children ...why does this child seem to behave differently.
2. Difficult for mother to see her son NOT thriving being normal	I was soon in tears because....she thought he was intelligent because she knew he could read His teachers she said, I'm afraid one day he was rolling around on the floor like a baby....when she said rolling around on the floor I could imagine he did that, I didn't doubt her but when she said that.
2. Shattering of parents	I sat there with tears rolling down my cheeks. Not

expectations of having 'normal' child - child seen as odd	want a parent wants to hear.
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- **Mother questions her own parenting/ can I parent?**

- Parent felt maybe not done enough or done something wrong - is to blame, felt judged by others – teachers and professionals
- Parenting in extremes, which was led by frustration – feelings of guilt
- Feelings of failure - should I/could I have done more – questioning if could have helped son more
- Using their parenting experience to help others
- Effects of parenting made the parents to decided not to have any more children

Comments	Participant Quotes
1.Parents evening seen as a judgement of parenting skills	Parents evening at school I suppose we were a bit nervous anyway.
1.Mother felt judged by others because child behaved differently	I feel, felt that the other parents would look at him and whether I felt at the time they were making judgements about me as a mother
Mother led to extreme behaviours due to feelings of frustration – unhealthy ways of coping – ashamed by this	Going back to the frustration...initially when he was very small. I know this is not a very nice thing to hear but erm I have some sympathy with parents who do struggle with their offspring and find it hard to vent those feelings out...you are going to think aren't I horrible at times I shook him because what do I do. I remember feeling very bad once because he ended up with a bruise on his arm and I still think that was because of me
Feelings of failure in mother felt unable to do her job as a mother – helplessness?	deep down I felt a failure because I'm his mum. I should have the answers. I should if anybody should know what to do or where to go surely it should be me.
Retribution help others not make the mistakes go through the stresses they went through	I mean we are ok now hopefully we can help others with disabled children.
7.Parent question if gave up didn't persevere enough to get their child support	Wondered perhaps could we have done more gone to the doctor. I don't know tried. I don't know yeah.

8. parent felt unable to parent another child even though wanted to due to the experiences of their AS child	We decided not to have any more children P being hard work...So we didn't I would have like to but it wasn't to be
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- **Feeling overwhelmed by parenting the unknown**

- Parents appeared to struggle to parent the unknown
- Parent potentially felt ashamed of child's behaviour
- Life was difficult led to mental health difficulties

Comments	Participant Quotes
1. Feeling overwhelmed unable to cope	I used to ring his dad up at work and I was in tears because I was so frustrated. Yeah. Not easy.
4. Hopeless of situation?? led to feelings of depressed	I felt depressed at times, definitely depressed
6. Overwhelming life full of stress led to MH issues in the mother	I have been treated for depression so that is why I don't say that lightly, especially with our sons

- **Support for parents - what got them through it**

- Religion

Comments	Participant Quotes
6. Religion got them through difficult times	I believe we were very very blessed. We are very much Christians and our faith is everything to us....wonderful Christian friends that prayed with us and for us and supported

- **Interpersonal relationships**

- Frustration among siblings - led to violence through lack of understanding of each other's behaviour HOWEVER through understanding formed a relationship –family is family
- Support from husband to get through a difficult upbringing

Comments	Participant Quotes
2. Frustration among siblings – resorted to violence	It did on his brother...out of frustration but he used to hit him
Support from husband how got through the stresses in life	37 years me and my husband have been married...I know and we are more in love. And that is all I ever wanted and then to have 2
9. Despite difficulties still had a relationship with brother	. I know this with all my heart he understands him better than me and his dad do.

- **Interaction with services**

- Having to **battle** to be listened to – having to fight for support/going against the establishment/ the system
- Not believed - parents don't know what they talking about - services not listening
- Did not feel supported – on 'your own'
- Services 'did not fit' their child
- Parent felt let down by services - parent felt child had an unfair life.
- Parent felt missed out on years of not being able to understanding their child and make sense of their own struggles
- Services perceived to be unaware of Asperger syndrome – parents attempt to sympathise with teachers was difficult - they are professionals they should have known

Comments	Participant Quotes
3.Dealing with teachers battle – constant trying to explain understand defend own child	Yeah arguments I guess you could say. Yeah certainly discussions with the teachers and erm because we were accused once
3.Insensitive nature of how others who should have been caring described their child	I have been teaching in high school for 30 years now and I have never ever come across somebody like you son. And to me that was insulting.
3.Services were seen as pointless/unhelpful	special needs complete rubbish....total rubbish it was a complete farce
4.Parents did not feel listened to concerns not heard – maybe professionals could not help what they did not understand	we weren't believed this is nothing to do with P
4.Parents did not feel supported	We certainly didn't feel supported as a parent. very bad, very bad.
4.Made to inferior by people in positions of power	like they were somehow better than us
4.Parents struggle to get help – battle	he has always known the struggles we had had with struggles as parents with his condition
5.Doesn't fit services or no service fit him – sense of exclusion	initially P got pushed from pillar to post
6.Child deprived of adequate care and support – life was unfair felt this was because of professional failures	must have been someone they could have gone to if they were gonna do their job properly...be professional give him the care that he deserved as a pupil. Yeah unfair depressing, not fair.

6.Difficult to think of teachers positively angry that they should have been able to help	I shouldn't be so hard on them because we didn't know what it was you know. But I still feel quite passionately there must have been back then,
6.Idea of a battle - outnumbered but triumphed	because it's not easy to go against the system
11.Difficult to believe that professionals missed his condition not diagnosed	perhaps we were just unlucky
11.Child was seen as naughty	teacher she saw it has misbehaving so she treated it with punishment so to realise it was not at all a condition to use for one for a better to express myself
11.If people understood life could have been different for child less struggling	she said if only I had known. So she would have been in her job as teacher obviously she would have been better empowered, equipped if there was somewhere recognise and told us why he had had all the struggles.

- **Hidden disability**

- If can't see anything to investigate not looked into

Comments	Participant Quotes
3.Son was neglected – nobody bothered to help – hidden disability - no one tried to help – mother saw it as personal they didn't care	Their needs weren't being met. They didn't investigate or start looking in to it or make an attempt to what might be going on with P in his mind in his head whatever...honesty they didn't care
6.Nobody wanted to know the problems, hidden disability	Nobody listened nor the doctors

- **Parent normalising their child**

- Not seeing the condition as different or as a 'condition' – denial/protective factor

Comments	Participant Quotes
4.Condition seen as not the right thing to say – denial – son seen as normal, not disabled but some ways disabled – feels like conflicting thoughts	I don't mean that because to us he is normal. There is nothing wrong with him. Yes shall we say he struggles in some ways erm but yeah we don't even see him as disabled. I know the world and perhaps medical would label him, as yes he is disabled in some areas.

- **Diagnosis**

- Sense of relief – somebody listened to them – took a long time
- Health professionals views on why intent on seeking a diagnosis - unable to understand how much the diagnosis means to the child
- Diagnosis was like a validation of the parents experiences, their feelings and thoughts about their child - burden had been lifted not because of their parenting
- Relentless nature of their child how their child got their diagnosis
- Diagnosis provided an understanding of the child –began to see how the child sees the world

Comments	Participant Quotes
4.found the diagnosis excellent but was a lengthy journey – idea of a battle	Excellent, well erm initially bless him he erm. It was quite a long process
4.Discussion with HP what does a label mean – made out to be something unwanted	he was told to learn some life skills....you don't want a label just get on with your life
5.Feeling of liberation having their concerns heard	It was just awesome at last there was someone who understood me and his dad.
6.Having to be relentless for a diagnosis	I know it was he kept on and on.
7.Recognition not bad parents – had a child that was different guilt shame been lifted	I could float up in the air. Like a great burden had been lifted at last....And thankful, hugely relived and thankful.
7.Diagnosis provided a new understanding of their child	Still P would share things. And I would say I'm sorry I didn't know that. One is light sensitivity and audio
7.Diagnosis pointed parents into right direction, finally knew what looking for	If there is something on autism on the television especially aspergers. I'll watch that

- **The future**

- Educate professionals - reduce the lack of understanding
- Treat parents with respect listen to their concerns
- Support groups need to be provided by NHS/organisations should not have to rely on volunteers

Comments	Participant Quotes
9.Professionals front line GP should be educated so can signpost adequately	First person you are going to go to is your GP... future if doctors know or could point people families in the direction of where to go.

10. Parents need to be listened to and have their experience validated as well as their emotions – professionals can be dismissive	were other professionals erm that could diagnose what in children but to listen as well Not to be dismissive. Don't just listen to the words try to listen in between the words.
9. AS people do not fit in MH services need a diagnosis service	Not as mental health but get them get them diagnose
9. Support groups are needed however should be provided by services should not have to rely on volunteers	Groups like this. But this is because, not because the professionals getting it right. This is just people volunteers.

- **Feeling proud at their child's achievement**

Comments	Participant Quotes
Parents bursting with proudness and own child's achievement	I was so proud as a parents, he said it was one of the best written English that he got.
6. Parents proud that child did not give up and persevered where they may have seen themselves to fail	I mean we didn't get anywhere....I actually admire my son because that showed determination....he showed great strength and courage

Appendix 18: An example of the development of the Super-ordinate themes, its sub themes and excerpts from the participants.

- **Super-ordinate theme 2: ‘services fumbling in the dark’**
- **Lack of awareness and appropriateness of services**

overall feeling of being let down by those that should have been able to help – especially schools	All refer to it except mark and Celia
services did not know what was wrong with the child – fumbling in the dark – did not know what they were looking for – lack of understanding and recognition in the professional world	All felt this, However Mark child had other co-morbid difficulties
Lived a life of being mistreated - parents felt that care received was unhelpful – did not know what type of support should be receiving. Parents appeared to not want to question the support they were getting because were grateful were receiving some support. Parents felt the care did not ‘fit’ their child – incongruent to their level of need. inappropriate services offspring and that they were made to fix boxes rather services fitting them	James, Rose, Laura those that got intervention
Parents think how life could have been different	Laura, Mary, James
Battle for services/having to fight to get statement, get support, social service support	Beth, Rose, Mary reference to it
Support that was received post diagnosis was flaky not substantial enough - again lack of recognition of the extent to which Asperger syndrome effects life. Not good enough doesn’t fit	Beth, Lilly

Participant extracts	
Rose	<p>with X refusing to get back on the minibus and they phoned me saying they didn't know where he was. So they were some real upset...I calmed him down and he was so I had to do something about it, a lot of soothing and calming and talking. So I couldn't just do it all....I was exhausted cos I was doing everything. 12</p> <p>had problems with people who help people who are vulnerable and their the people that are a pain in the arse 13</p> <p>job centre was not so good they were sending him for jobs like front line of the police station with someone with communication difficulties no I don't think so. Organising accommodation for people in the army and they said they will stop his money 14</p> <p>nobody ever mentioned asperger or autism...this woman was on a different plane I suppose...I suppose she didn't quite know what to make of him 5</p> <p>I mean no recognition...now and after wards I thought flippin heck. 5</p> <p>I thought right now we have got this something great but there were no services...can't get anything unless you got a social worker, like housing or support or advocacy... phoned social services and no we can't do anything he is too able...He doesn't need help dressing and he can wash. 15</p>
Laura	<p>this has been [son] problem throughout his education he didn't get the labelling he didn't get the support 1</p> <p>did not feel natural to be doing that. 1</p> <p>I was pleased when he was discharged from there because it was somewhat distressing taking my son there....had to understand that there was certain areas of his development that did need help so I let him go there but I wasn't very happy about it. 1</p> <p>I didn't know what would be more appropriate I just didn't feel happy. 1</p> <p>Referred...to the child development centre...being told that he needed to come out of that environment cos his problems were so mild that in a way there was a danger he would be influenced by watching more severe effected children. 1</p> <p>If he had been diagnosed and somebody sitting with him...he never had that 1:1</p>

Beth	<p>he did this course there and they it sounded very good as if they were going to help him get a job and the support would be there when he got a job. And that all fizzled out.15</p> <p>now I know people that have to fight to get their child statemented15</p> <p>They were desperate at school they were just not...The support was just not there. I think it is always the children that need it the post that just don't get it7</p> <p>we saw several people up there over a number of years. They were very good very helpful but all they could say was all the wires are there but something is not quite connecting. So we just sort of persevered I suppose....well it was a bit frustrating 1</p> <p>you need to have that support and it needs to be a continuing support. 17</p> <p>The lady who came...I don't think suitable for what's she was doing. She used to get cross with (son) because he couldn't learn the alphabet properly....I think she was asking too much 8</p>
Lilly	<p>so I think lot of doctors don't know. It's appalling really 11</p> <p>The doctor...used to see her for 5 or 15 minutes. He never remembered what they talked about and he thought she was depressed.11</p> <p>he also thought she had been abused.5</p> <p>She had been bullied in the actual classroom, sort of verbal bullying. I don't know why the teachers can't notice it. I think the teachers were having a rough time anyway. 4</p> <p>looked for a befriending...she went to look for a charity for Asperger syndrome ...She joined various groups but they didn't cater for her. They weren't as bright as her. Or they would meet in these noisy pubs or church rooms and they weren't suitable 9</p>
Mary	<p>special needs complete rubbish....total rubbish it was a complete farce3</p> <p>he has always known the struggles we had had with struggles as parents with his condition 4</p> <p>initially P got pushed from pillar to post 5</p> <p>must have been someone they could have gone to if they were gonna do their job properly...be professional give him the care that he</p>

	<p>deserved as a pupil. Yeah unfair depressing, not fair.....5</p> <p>I shouldn't be so hard on them because we didn't know what it was you know. But I still feel quite passionately there must have been back then, 6</p> <p>because it's not easy to go against the system 6</p> <p>teacher she saw it has misbehaving so she treated it with punishment so to realise it was not at all a condition to use for one for a better to express myself...she said if only I had known. So she would have been in her job as teacher obviously she would have been better empowered, equipped if there was somewhere recognise and told us why he had had all the struggles. 11</p>
Mark	Well you got to blame the teachers; you got to blame the headmaster. 1
James	<p>X found it very very difficult to communicate in a way that is appropriate....than formed inappropriate ways of communicating...sort of self harming types 2</p> <p>very difficult dealing with health services...you know leave the psychiatry to the psychiatrist, you get on and do the medical bit. 3</p> <p>when you got aspergers and you're dealing with mental health and medical and all the rest of it you don't fit in the right box. You are in a box but you have got another need. 4</p> <p>And what you find is none of the services are connected up and that is extremely frustrating. that in itself can almost be more stressful than dealing with the child 4</p> <p>have been phenomenal 5 stars with a little tick at the end 8</p> <p>child social services diabolical doesn't even go there at times. 9</p> <p>A and E get involved, psychiatrist and you just look at the list this is costing thousands and thousands because somebody can't see the big picture 9</p> <p>social service....they make decisions and they change the plan instantly and x doesn't change plans instantly. It's like an ocean liner it takes about 4 weeks to change directionnow lit the blue touch paperstart to stress up through the week with the realisation of what's going</p>

	on has happened and then explode at the end of the week 9
Celia	

- **Parents perceptions of services / how parents felt with the way they were treated by services seen as 'just a parent'**

<p>Parent felt not listened to - dismissed by services. Parents described being made to feel insignificant. Their beliefs invalidated not taken into consideration.</p> <p>Felt as if they were treated rudely by professionals (especially Rose) – some parents felt professionals did not make enough of an effort with their child. – may have felt professionals did not try because of their lack of awareness of AS. Led parents to feel that professionals did not 'bother'.</p>	All except Mark, Celia little contact with services
<p>Because professionals unable to offer an explanation of their child's difficulties – may have contributed to the self blame beliefs that the parents held.</p> <p>Some professionals assumed parents wanted diagnosis for themselves rather than their child.</p>	Rose direct - Mary, Laura,
<p>When listened to hugely grateful/ felt acknowledged – validation of their feelings.</p>	James, rose, Mary, Laura some

Participant extracts	
Rose	<p>I thought what the hell, it was so offensive'. 4</p> <p>And I was just sitting there outside, I was in tears it was just so [inaudible] he didn't even say do you have any problems with him at home.' 4</p> <p>My son being treated like you know like shit really. 4</p> <p>Felt put down and crept away' - insignificant insect – 'he had a medical student with him and was busy showing off to him and...[son] buried himself and he was curling up as if he didn't want to be seen. And I said I'm...sorry...Perhaps he offended the paediatrician...gave him a physical examination like he was a beetle. He wasn't particularly nice to him. He was about 4 and said there is nothing wrong with him he's fine, go away...I didn't have the thing to fight because I was depressed. I just felt put down and...crept away. I wasn't sure what he did and I didn't understand about Aspergers'. 3 'like a beetle'3</p> <p>I went to see my GP and who I said previously I think he's got Asperger syndrome ...response I got was it won't make him integrate any better the diagnosis is for parents. Erm which sounds horrid 5</p>
Laura	<p>you trust in their competence because they're the ones that are professionals and your not you believe what they say.... you're a bit reverential to people with qualifications 3</p> <p>they helped academically, there wasn't really any interest paid in his other problems 6</p> <p>I think it came from me I don't think anyone was offering, could X be assessed 6</p>
Beth	<p>I said to be quite honest I have never seen an IQ test so badly done. And I was more or less told what do I know I was only a parent. 1</p> <p>I have taught mentally handicapped children all my life and he is not mentally handicapped.... I'm afraid he went back to our doctor and said we don't like the diagnosis and we don't agree with the diagnosis. 1</p>
Lilly	<p>teachers at one stage asked the children what they had for breakfast and I think she was sort of ridiculed because she had asked for a ham sandwich....found these ham sandwich in the settee and it makes you feel awful because you rather your child said I don't want those mother don't do it 8</p>

Mary	<p>Yeah arguments I guess you could say. Yeah certainly discussions with the teachers and erm because we were accused once 3</p> <p>I have been teaching in high school for 30 years now and I have never ever come across somebody like you son. And to me that was insulting.3</p> <p>we weren't believed this is nothing to do with P 4</p> <p>We certainly didn't feel supported as a parent. very bad, very bad. 4</p> <p>like they were somehow better than us4</p>
Mark	Other health professionals I think are awful.
James	<p>irritating in that you think it messes our lives up and messes her life up. 9</p> <p>want to say to these people take a hike I'll take her home and sort this mess out myself because I will do a better job than you will. 4</p> <p>Its irritating in that when you lived with this child....you know what's going to happen. You know the triggers that are going to cause an explosion. You know how to calm them down and what to do when dealing with professionals and they tell you know it's going to be done this wayyou just got home you get the phone call they've pressed the button. She's gone off they've gone off she gone off even further and you....think does anybody listen (laughter). 3</p> <p>raise an issue therefore health respond, she would then respond they would then have to respond and you go round in this quite vicious circle and things escalate to a very high level very very quickly. Often a couple of hours you can go from a difficult situation to an absolute crisis. 2</p>
Celia	

Appendix 19: Table of further participant extracts for each super-ordinate theme and the respective sub themes.

Super-ordinate theme 1: 'Parenting the unknown'

• **Sub theme 1: Unable to make sense of their child's difficulties**

'I was very watchful and concerned which I didn't realise...I was always watching him and wondering and trying to work it out'. (Rose, 403-406)

'We had many discussions I guess me and his dad and other people discussed why this apparently intelligent child was struggling with the simple things in life' (Mary, 54-57)

'You are trying to work out and you just can't work out why with these obsessions. And er that could be frustrating' (James, 30-31)

- ❖ parents ruled out the possibility of an Autism disorder because they were unaware of the range of ASD presentations

'I have met autistic children in the past and I don't think I even realised that there was quite this spectrum. I think they were just a little bit odd'. (Beth, 244-246)

- ❖ parents appeared to perceive others as judgemental

'The remarks begin. Where people have opinions about what you're doing. You think this is my son and you don't actually know anything about how he is. That was a bit hurtful' (Rose, 236-240)

- ❖ Parents spoke lovingly of their child and proud of what they have achieved despite their difficulties.

'It was about 150 employees...she's the one with Aspergers. They would all go to her'. (Lilly, 254-256)

'He is the sweetest. kindest person and he has got a very lovely nature' (Rose, 275)

- **Sub theme 2: Self blame**

'Wondered perhaps could we have done more gone to the doctor. I don't know tried'
(Mary, 272-273)

*'You feel you are letting your kid down. But you think hang on if I continue in this way
the other 2 are gonna be destroyed as well'.(James, 509-511)*

- ❖ parents appeared to question whether their parenting interventions
contributed to their child's difficulties

*'Am I doing it right I'm probably not but I just didn't know what else to do' (Rose, 388-
389)*

*'Deep down I felt a failure because I'm his mum. I should have the answers. I should if
anybody should know what to do or where to go surely it should be me'. (Mary, 170-
173)*

- ❖ parents felt hugely relieved when their offspring received a diagnosis of
Asperger Syndrome

*'I think relieved and I think I felt glad and I thought there you go cos I felt guilty' (Rose,
599-560)*

*'Start to think I am not a bad parent I haven't got this wrong...I actually have a child
that's different an unusual personality. And you deal with it appropriately'. (James, 209-
212)*

- ❖ Parents experience of mental health difficulties

*'I have been treated for depression so that is why I don't say that lightly, especially with
our sons' (Mary, 206-208)*

*'I was depressed... for a period I was suicidal (502-503) I pulled myself along. I feel
really proud of it actually...I climbed out the abyss' (Rose, 519-520)*

❖ Parents protective factors

'We are very much Christians and our faith is everything to us. Wonderful Christian friends that prayed with us and for us and supported' (Mary, 209-212)

'I had my mum and dad I could talk to...I think it is very important for parents wherever their problems there is someone else to talk to ...You realise you are not alone' (Beth, 487-488)

- **Sub theme 3: Death of the 'normal' child**

'He was doing everybody's rubix cube in a few seconds....brilliant that he could do that...didn't think it was odd that he was a just a very gifted young child'. (Celia, 24-27)

'Not surprised. Sad...makes you look bad and think he did not have what he needed throughout his education' (Laura, 235-237)

'My husband found it more frustrating....men want the sort of kid that plays football and that sort of thing.... Because a man wants you know a real boy'. (Beth, 367-372)

Super-ordinate theme 2: 'Services fumbling in the dark'

- **Sub theme 1: Lack of awareness and appropriateness of services**

'We saw several people... over a number of years. They were very good very helpful but all they could say was all the wires are there but something is not quite connecting. So we...persevered...it was a bit frustrating ' (Beth, 30-34)

'When you got aspergers and you're dealing with mental health and medical and all the rest of it you don't fit in the right box. You are in a box but you have got another need'. (James, 157-160)

'They helped academically, there wasn't really any interest paid in his other problems' (Laura, 207-208)

'So I think lot of doctors don't know. It's appalling really' (Lilly, 462-463)

'Teachers at one stage asked the children what they had for breakfast and I think she was sort of ridiculed because she had asked for a ham sandwich....found these ham sandwich in the settee and it makes you feel awful' (Lilly, 310-314)

- **Sub theme 2: 'Just a parent'**

'[Paediatrician] gave him a physical examination like he was a beetle...He was about 4 and said there is nothing wrong with him he's fine, go away...I didn't have the thing to fight because I was depressed. I just felt put down and...crept away'. (Rose, 118-122)

'Like they [professionals] were somehow better than us' (Mary, 134)

'Social service....they make decisions and they change the plan instantly and [daughter] doesn't...It's like an ocean liner it takes about 4 weeks to change direction.. start to stress up through the week with the realisation of what's going on...then explode at the end of the week' (James, 342-352)

Super-ordinate theme 3: 'Fear of the future'

- **Sub theme 1: The uncertain future**

'We will try when we are not around anymore to have made him at least partially independent (356-357)...I don't think its siblings job to be a surrogate parents for him' (Laura, 364)

'What would be best for him with his future in mind knowing that we are not going to be here forever and things can't continue as they are' (Laura, 449-451)

'We have set up a trust fund with his sister as the executive...we say it is for when we are not around anymore'. (Beth, 448-450)

- **Sub theme 2: what we need for our children to *live* rather than *exist*.**

'I was working with deaf children...I used to go out once a week to check you know are there any problems...There is nothing like that' (Beth, 557-561)

'That is where you need a moderator and they just don't exist' (Beth, 590-591)

'It is important really they get some help because they can't fight for themselves'. (Lilly, 452-453)

'Can have a scheme you can have a team of people....if somebody popped in...somewhere to go to socialise....drop in place...would have somewhere to go, cup of coffee, advice, it's that safety net'. (Rose, 619-629)

❖ Importance of educating wider services

'Facilities for employers...if you can get them in the right job they are more reliable...give them an opportunity' (James, 541-546)
